

• ***Articles*** •

“They all see dead people—but we (do)n’t want to tell you about it”:
On Legend Gathering in Real and Cyberspace

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Abstract: This essay explores the relationship between traditional and digital legend telling through a comparison of hospice staff’s stories of their patients’ deathbed visions (DBV), online and off. DBV narratives are typically those in which witnesses report that a terminally-ill person seems to speak to or otherwise interact with a person or persons, not seen by others in the room, who have come to take him or her to the “other world,” however defined, shortly before his or her own death. The author experienced a field research crisis when she found hospice staff and volunteers were posting narratives in cyberspace that hospice staff would not reveal in face-to-face interviews, and wanted to know why. The following article reports on the author’s findings, and discusses how ethnographers, traditional and/or virtual, might draw on hybridized legend patterns for more complex and sensitive readings of that storied phenomenon we call death.

Introduction

This article is something of a meditation on legend gathering, both face-to-face and online, and on how these different field research modes might affect data collection and analysis—and why that might matter.¹ These reflections have come to me somewhat late, given the millennial groundswell of publications about the relationship of traditional folk genres and new social media, on the one hand, and of traditional and virtual ethnography, on the other.² It took a field research crisis, however, for me to examine my own position vis-à-vis digital culture. Locating this position is important for me to recognize personally, of course, but it has somewhat broader import because I represent both older social media users who were adults when the Internet was first introduced, whom folklorist Lynne S. McNeill has called “digital immigrants,” following educational theorist Marc Prensky (2001, 2; cited in McNeill 2009, 81), and traditional ethnographers who were “hesitant to engage

the [Internet] format" (Blank 2009, 4), but who are now some of the newest expanding user groups (Madden 2010).

The "Other Worlds" Project Background

In 2002, I proposed a qualitative ethnographic project designed to record and analyze unusual, paranormal, supernatural, or mystical³ narratives in situations that are health-related, often end-of-life, which my university's Institutional Review Board approved under its behavioral research arm. The "Other Worlds"⁴ study began when my long-standing interest in legend studies and my own grappling with serious illness crystallized in a moment in the spring of that year. In trying to comfort one of my younger brothers at the memorial service for his wife, I remembered a defining line from folklorist and medical humanist David J. Hufford's chapter, "Beings without Bodies," in *Out of the Ordinary: Folklore and the Supernatural*:

My conclusion about the rational and the empirical elements of spiritual belief—its reasonableness—grows out of my experience-centered study of beliefs about supernatural assault, mystical experience, miraculous healing, consoling visits by the deceased to the grieving, near-death experiences, and haunted houses among others. (1995, 19)

When I told my brother that he shouldn't worry if he felt his late wife's presence because it was a normal part of bereavement for some individuals, he told me that that was one of the first things the hospice staff had told him. Our exchange then in that time of sorrow was my entrée into more than a decade of research still ongoing. It prompted me initially to ask how medical personnel, families and friends of ill persons, and ill persons themselves⁵ spoke about "the return of the dead," a subject that I had previously linked only with supernatural legends and personal experience narratives connected to place, to haunted houses, and to other ghostly locations.⁶ To find answers to that question, I began conducting field research with individuals in a convenience sample and with staff and volunteers at a local, free-standing hospice in 2003.⁷

Once I began reviewing multidisciplinary literature in the course of the study, I found that the narrative theme of the dead returning, especially as it relates to questions of

life after death and to the nature of human consciousness, has been addressed in medical contexts—not without controversy—for well over a century.⁸ My expanded (and daunting) goal for the overall “Other Worlds” project now is to see how folk narrative approaches (legend work in particular) draw from and contribute to expert and lay discussions about supernatural experiences and health, especially in stressed-filled times of illness and accident, impending death, and bereavement. This essay points to problems on the way.

The Crisis

Although researchers disagree on the meanings of revenant accounts in health contexts, they do seem to agree on three basic kinds of stories in which the dead come back: **1.)** Reports of a bereaved person sensing or seeing the recently-deceased loved one who has returned from “the other world,” however defined, to give comfort to the survivor are examples of what some call After-Death Communication (ADC);⁹ **2.)** Near-Death Experiences (NDE) narratives tell of a person, presumed to be clinically dead for a brief period, who regains consciousness and talks about experiencing a sense of peace, going through a tunnel to a white light and often being greeted by deceased loved ones, religious figures, or unknown people in an otherworldly setting before awakening;¹⁰ **3.)** Deathbed Vision (DBV) accounts—less known generally than NDE accounts but related to them thematically at the very least¹¹—are those in which witnesses report that a terminally-ill person seems to speak to or otherwise interact with a person or persons, not seen by others in the room, who have come to take him or her to the other world shortly before his or her own death.¹²

All these narratives and their permutations and fragmentations appear in my “Other Worlds” field research data, but I examine only deathbed visions narratives in this essay because they reveal both my difficulties with traditional ethnography and my initiation into cyberethnography. I did *not* initially draw on online resources, but did so when I googled “deathbed visions” for the first time in 2011. I chose this subject because it was the category of story about which I knew least, and the one that the hospice staff¹³ and volunteers I interviewed talked about most—when they did speak to me. Early in my field research at the hospice, a certified nurse assistant had leaned over my shoulder and said

that staff had witnessed or heard about their patients' mystical experiences, but that they did not wish to discuss them with me. I took their reluctance as a given, without examining their reticence more fully, and allowed it to guide my research in subsequent years. I saw each questionnaire completed and interview granted as a gift (and still do). Other field researchers found staff and volunteers of hospices, hospitals, and nursing homes reluctant to speak to them about their patients' supernatural experiences also. Parapsychologists Karlis Osis and Erlender Haraldsson had written in their classic study, *At the Hour of Death*, "In the late 1950s [when the authors' surveys with doctors and nurses began], professional circles held much stronger bias against paranormal phenomena than they do now" (1997 [1977], 29). Yet psychologist Marilyn Mendoza (2008) found a similar response when she administered questionnaires to nursing staff in Louisiana and Maryland. She commented in an interview that "even those who witness deathbed visions may be hesitant to say they have. A lot of people don't talk about this because they think people will think they are crazy, but every time I mentioned this to someone, they had a story" (quoted in Bynum 2009).

So it came as a shock, a complete shock to me, when my initial foray into the Internet yielded over 250,000 results¹⁴ which included websites where researchers as well as hospice, hospital, or nursing home staff and volunteers discussed those very narrative events that had eluded me. It occasioned, I must confess, a *cri de cœur* on my part—"Why will they talk to each other online and not to me?" That question (and the fact that I asked it so late) proves that I am still one of the "dwellers on the threshold between the real and the virtual, unsure of our footing, inventing ourselves as we go along" (Turkle 1995, 10; quoted by Tucker 2009, 67, 79), and not a "digital native" for whom the real and the virtual merge (McClelland 2000, 182, as cited in Blank 2009, 2; McNeill 2009, 84). Now I wanted answers to that question.

The Resolve that Occasioned This Essay

A hospice nurse wrote in her "Other Worlds" questionnaire that she and another nurse were doing wound care for a patient, each nurse on either side of the older man, when the patient smiled at the end of his bed and "called out to Johnny—asked where he

had been, expressed he really had missed him [and] stated ‘so glad you could come for me’—then turned toward the nurses and said, “Isn’t he great—always loved my brother.” The nurses saw no one else in the room and the patient died the next day (OWIIA.012).¹⁵ Her report of her patient’s deathbed vision showed that he had experienced dual planes of reality simultaneously—he talked to his brother Johnny who had predeceased him and to his caretakers equally coherently before his death.

In his classic study of deathbed visions, Sir William Barrett, a physics professor at the Royal College of Science in Dublin and a psychical researcher, discussed the 1924 case of a young mother who experienced the same duality while dying of heart failure soon after the birth of her healthy baby. Sir William’s wife, Lady Florence Barrett, her attending obstetrician at Mothers’ Hospital in London, reported to him succinctly, “She lived for another hour, and appeared to have retained to the last the *double consciousness* of those bright forms she saw and also of those attending her at the bedside” (Barrett 1986 [1926], 12; emphasis added).¹⁶

In an eerie parallel,¹⁷ anthropologist Michael M. J. Fischer (1986) wrote that ethnographers had to consider “bifocality” or “dual tracking” for their field research to be effective. Field research, like the ethnic autobiography and fiction to which he compared it, “must increasingly be a shorthand for ‘two or more’ cultures in juxtaposition and comparison” (198-99). Although Fischer was writing before the digital age fully emerged, his concepts apply to my examination of the intersection of analog and digital deathbed visions narratives. Double tracking becomes both a model of and for my quest to understand how and why it might be easier for hospice staff and volunteers to speak of their patients’ visions online than to ethnographers and others offline. The following sections report on my findings. The first section compares DBV experts’ websites to their publications offline. The second section compares websites maintained by hospice staff and volunteers to their face-to-face communication and to experts’ websites. The concluding section assesses how ethnographers, traditional and/or virtual, might draw on these communication patterns in real and in cyberspace for more complex and sensitive readings of that storied phenomenon we call death (see Gefland et al. 2005, xxiii-xxx, 1-25).

On the Elite Web as Orientation

My initial mental map of deathbed visions websites corresponds to folklorist Simon Bronner's understanding of the modernist tendency to construct binaries, "especially folk and official," both culturally and digitally (2009, 22). My review distinguished deathbed visions websites constructed by DBV experts from those maintained by hospice, hospital, and nursing home staff and volunteers in the trenches.¹⁸ Generally speaking, the experts' sites do "control content and broadcast information to a passive viewing audience," while the folk or vernacular sites "allow posting, 'live' chat, and free exchange" (Bronner 2009, 23). A discussion of three representative sites follows as an orientation strategy to gauge the range of expert positions.¹⁹

Caring for the Dying

One of the first and most stable websites I visited was Dr. Michael Barbato's "Caring for the Dying." The parallel between analog and digital communication is most clear on its homepage designed to present the author's books as available for purchase. I recognize the site's top-of-the page banner image of the sun setting in clouds as an iconographic motif in book covers in the analog world and as a meme in the digital world of deathbed vision literature, its end-of-day, end-of-life parallel clear.²⁰ The website's "essays" link contains information on related topics which are distillations of Barbato's "how to" books, written for a broad audience of professional and home caregivers, based on his twenty years as a palliative care doctor in Australia. The "contact" link allows individual users to write to him, but the messages are not public. Furthermore, Barbato posts in the "author" section that he "has a long-standing interest in unusual experiences around the time of death."

Although not mentioned on the website, Barbato led an interdisciplinary medical field research team surveying the prevalence of deathbed visions among terminally-ill patients, whose report was one of the first published in the *Journal of Palliative Care* (Barbato et al. 1999). Comprised of medical doctors, social workers, and psychiatrists, the team analyzed responses to questionnaires sent to one hundred family members of patients who had died in the Palliative Care Unit at St. Joseph's Hospital (Auburn, New

South Wales, Australia), one month after their deaths. The team reported that the forty-seven relatives who responded noted that patients had a “sense of a presence” (50 percent) or of a “visual hallucination” (5 percent) among other unusual events before they had passed away (Barbato et al. 1999, 32). The team’s conclusions at that time were directed to professional caregivers and medical researchers:

Even if we cannot understand the basis for the parapsychological phenomena, the weight of evidence suggests we cannot continue to ignore them. They are common and frequently misunderstood by the experiencers, relatives, friends, and caregivers. As part of our professional role in palliative care we can help to normalize these experiences by inquiring after and inviting grieving subjects to talk about any unusual event around the time of or subsequently to the death of their loved ones.²¹ (36)

The authority of Barbato’s website rests on his team’s earlier study for me (Barbato et al. 1999). Though the latter was basically a quantitative research project, it created space for narrative possibilities by allowing “grieving subjects to talk,” asking them to give examples of their relatives’ deathbed visions, thereby allowing them to record summaries of their memorates or personal experience narratives of the supernatural (see Dégh and Vázsonyi 1974).²² The website’s orientation echoes and extends this earlier research model geared to patient care, seen most clearly in its “[**deathbed visions**](#)” essay link where Barbato ties together the analog and digital worlds through narrative:

Those who have read *Reflections of a Setting Sun* will recognize the following anecdote. The words were spoken by an elderly Italian matriarch (Nina) whose family had insisted she not be told she was dying of cancer. As she gazed upon a scene, invisible to everyone else in the room, she gesticulated and, directing her words to the family, she gleefully announced, “my bags are packed, my boat has come, I am going on a beautiful holiday and none of you can come with me.” In this case, it was not Nina, but the family who needed to have the vision validated and normalised. Once they knew the significance of the vision they were, for the first time, able to speak openly to Nina about her

illness and impending death. The vision was ultimately healing for them as well as Nina.

Barbato notes in his online essay that the cause of deathbed visions “is open to speculation” as “none of the current theories adequately explain why they occur, let alone their content.” He notes that caregivers should indeed be interested “in the debate surrounding life after death”²³ but “we at the bedside should not be distracted from a more pressing issue – what does a deathbed vision mean for the person having one?”

Horizon Research Foundation

While Barbato’s “Caring for the Dying” website connects one doctor’s online and offline work in understanding deathbed vision accounts in terms of patient care and survivors’ grief, it downplays his initial survey with patients’ families and the debate about the nature of these experiences. By contrast, “**Horizon Research Foundation: Science at the Horizon of Life**,” puts the debate on whether consciousness does or does not survive bodily death front and center by virtually amplifying the extensive research efforts of international scientific teams exploring “the mystery of what happens when we die and the nature of the human mind.”²⁴ In the site’s “**About Us**” link, the Editorial Board of the Foundation, an independent charitable organization based in Southampton General Hospital (Southampton, Hampshire, Great Britain), notes the “mind/body problem”: “Despite the current prevalence of materialistic (non-dualistic) theories versus non-materialistic (dualistic) ones, this editorial board will provide equal coverage to both since no theory has currently been proved through scientific research.” The Foundation’s homepage features an abstract logo—the letter “H”—indicative of the line between earth and sky, between life and death, at the nexus of the medical research it sponsors.²⁵

The place of narrative in this research is a complex one. Although Near-Death experience experts have amassed thousands of patients’ accounts over thirty years or more as research documents (Fenwick and Fenwick 1997; Holden et al. 2009), the website’s *raison d'être* is to go *beyond* narrative to study the Near-Death Experiences (NDE) phenomenon²⁶ through resuscitation studies among others. Within this context, the site’s deathbed visions (DBV) links have morphed during my periodic checks of the site. A brief

deathbed phenomena (DBP) definition remains on the “**near-death experiences**” link which has the top-of-the-page graphic of backlit clouds in an expansive blue sky I have come to expect. A “Death Bed Vision Study,” accessed through the “research zone” link in the past, is no longer accessible on the website, however.²⁷ The study’s eQuestionnaire was presented to potential participants as part of “a web-based investigation using online research tools to study the prevalence, phenomenology, and impact of End of Life Experiences (death bed visions).” The online study was designed to utilize “the power of the Internet to extend the sample,” and to complement ongoing field research studies in the United Kingdom.

I had known of two on-the-ground studies done by the online DBV research teams earlier, both published in the *American Journal of Hospice and Palliative Medicine*. The first examined the effects of deathbed phenomena (DBP)²⁸ on the palliative care team at the Camden Primary Care Trust in London (Brayne et al. 2006). The second compared the Camden pilot study results to those found among nurses and care assistants at a Gloucestershire nursing home (Brayne et al. 2008). In both analog studies, the team administered a five-year retrospective questionnaire with a follow-up taped interview, and then one year later, administered a one-year prospective questionnaire, testing to see if staff perceptions were altered by their participation in the survey. The eQuestionnaire, similar to the ones used offline, was also based on the Barbato model among others.

In their earlier ethnographic studies, the teams recorded deathbed phenomena similar to accounts I had recorded in the “Other Worlds” project. Staff reported patients having the vivid dreams and visions of deceased loved ones and religious figures under discussion in this essay; patients appearing to wait to die until the arrival of beloved relatives;²⁹ staff and patients seeing spectral children, animals, insects, and birds in patients’ rooms;³⁰ and staff experiencing changes in temperature in rooms where patients had died (Brayne et al. 2008, 199-201).³¹ Team findings also included staff attitudes about deathbed visions, essentially noting occupational stress factors. Staff stated that they had trouble distinguishing their patients’ deathbed visions from drug-induced hallucinations, that they were “ill-prepared to support patients with these experiences,” and that they were “reluctant to discuss these DBP [deathbed phenomena] amongst themselves or with

others outside their team" (Brayne et al. 2006, 19-24; 2008, 203-4). One of the eQuestionnaire's stated goals, related to these earlier results, was to find an answer to this question: "How easy carers find it to talk about such experiences, or whether they feel they will be laughed at or ridiculed if they talk about the experiences in an ordinary social setting." The results of the eQuestionnaire have not been published, online or off, to my knowledge.

Do the Dead Greet the Dying?

Narrative as testimony takes center stage in a dualist position in the deathbed visions debate in the last website (or series of websites) I examine. In the literature review posted for prospective participants in the now-defunct eQuestionnaire discussed above on the Horizon Research Foundation's website, teams traced the renewed medical interest in deathbed visions, at least initially, to Dr. Elisabeth Kübler-Ross's 1971 article, "What Is It Like to Be Dying?" first published in *The American Journal of Nursing*.³² Carol Zaleski calls the Swiss medical doctor, psychiatrist, and thanatologist credited with bringing the British-based hospice movement to the United States, "the revered but scandal-haunted apostle of humane treatment for the dying and their families" (1987, 97).

Kübler-Ross's (1969) *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy, and Their Own Families* is still the gold standard for treatment of the terminally ill and their caretakers. Several hospice staff and volunteers I interviewed in the "Other Worlds" project noted that her book, as well as her talks and workshops, brought them into hospice work. One volunteer and spiritual care coordinator, who had received the book after her mother died, said that she "was very impressed and touched with the simplicity and beauty of her premise, and that is: If you want to know what a dying person wants and needs, ask them. And then, unique in our society, listen to what they say" (OWIIA.025). Kübler-Ross's subsequent work (and those of other near-death researchers), positing "that the visionary testimony of her patients proves 'beyond a shadow of a doubt' that death is but a doorway to a better world" (Zaleski 1987, 97), has indeed been contested. Surgeon Sherwin B. Nuland writes, for example, that he does "not doubt the existence of the near-death phenomenon," but finds that "the comfort and peace, and

especially the conscious serenity, of final lingering days on earth have been vastly overestimated by many commentators; we are not well served by being lulled into unjustified expectations" (1995, 138-39). A hospice nurse told me that the hospice movement has gone beyond Kübler-Ross, and I wonder now what she meant and why I didn't ask her more (OW IIA.014).

David Kessler, Elisabeth Kübler-Ross's protégé, co-wrote two books with his mentor and was with her at her death in 2004. He has a strong presence both online and off. It is his book *Visions, Trips, and Crowded Rooms: Who and What You See Before You Die* (2011[2010]) and its online repercussions that claim my attention here. In "A Note to the Reader," Kessler describes the contributors to the book as "healthcare professionals and clergy members as well as those who have lost loved ones" who shared their firsthand accounts of deathbed visions with the author "in the hope that readers will come away less afraid and with a deeper understanding about what happens in our final moments in life" (xi). He concludes, "This book is simply a report from the front lines, featuring stories of average people, in their own words, experiencing extraordinary events" (xi). *Visions* is the first in my discussion here that deals overtly with folk narrative and with religious as well as secular concepts of the afterlife, represented most clearly by the accounts clergy shared with Kessler, but related to broader spirituality and health movements.

Intertwining of real and cyberspace emerges in *Vision's* "Afterthoughts." Kessler opens with an astute summary most current writers can appreciate: "Books are usually a one-way conversation in that the author shares information with his or her readers." "However," he continues, "the Internet has drastically changed all that. Today, I can write a book such as this one, or post an article online, and draw almost immediate responses to the work." He notes that he received "countless e-mails and thousands of comments about it," and was amazed that he could receive "more than 1,000 pages of comments for a book that was only 160 pages" (2011, 156).

The article (drawn from his book) that Kessler did post online, "[Who and What You See Before You Die](#)," was first posted on Oprah Winfrey's website, where Kessler had been a regular "Spirit" contributor, on June 22, 2010. This popular article was re-posted with the title "[Do the Dead Greet the Living?](#)" on television news channel CNN's website on October

19, 2010. Due in part to the response to his book and online article, Kessler was interviewed on CNN's "American Morning" shortly thereafter in conjunction with discussion of Clint Eastwood's film, *Hereafter* (2010), in which a reluctant medium converses with the dead. Kessler, along with other NDE experts, had been a consultant on that film. On the program, he stressed the need for people to recognize the validity of deathbed visions.³³ He told his own moving personal experience narrative—he saw the comfort his dying father drew from seeing his deceased wife, Kessler's mother, waiting for him. The [video clip](#) was posted on CNN.com, October 20, 2010, and [on YouTube](#), April 11, 2011.

Kessler's own thoughts about this online interest and feedback point to an intersection of the elite and vernacular webs that blurs but does not entirely erase my initial binary mental map of cyberspace. He simultaneously confirms his own status as a celebrity expert in the social media and recognizes that comments constitute a democratized virtual space where folk can interact with the institutional.³⁴ He presents this process of debate in a way that is remarkably legend-like, if not legendary itself (Dégh and Vázsonyi 1973), which foreshadows the patterns I explore more fully in the next section on the folk web. Moreover, he notes positive online feedback first: "There were stories, accounts from health-care professionals, and even video by family members describing what they'd witnessed" that gave evidence for life after death (Kessler 2011, 159). He then discusses negative feedback: "The article on CNN.com also served as a forum for those who don't believe in deathbed visions to voice their opinions" (2011, 159-60). He concludes by stating his own position: "I'm going to believe the words of the dying over the beliefs and doubts of the living who haven't lost a loved one or worked in a hospital or hospice setting" (2011, 162).

The deathbed visions experts' websites reviewed here have been constructed by researchers who have done fieldwork (the first two quantitative, the last qualitative) in the everyday world with patients, their families, doctors, and staff. They have professional interest in deathbed visions accounts, despite their different theoretical positions, methodologies, and perceptions of the place of narrative in their research. All the researchers reviewed here have used the Internet to enhance their goals. Their websites

are platforms for announcing their projects and promoting the workshops, forums, lectures, and publications that define them as experts. Yet their professional deathbed vision websites can have a “transgressive folk web” quality themselves, especially if their agenda is a double one (Bronner 2009, 22). To support dying patients, their families, and their caregivers by normalizing patients’ deathbed visions, as the “Caring for the Dying” website does, is one thing. But to consider proof of survival of human consciousness after physical death, whether through rigorous scientific experiments, as the “Horizon Research Foundation” website does or through patient or witness testimony as “Do the Dead Greet the Dying” websites do, is another. That goal, however differently expressed and contested, keeps these websites out of the mainstream (either on the fringe or on the cutting edge dependent on one’s perspective).

These websites, no matter their status, do reveal the major debates about life and death that have remained constant, although paradoxically shifting and nuanced over time, in recent discussions of near-death and end-of-life experiences in medical and public forums.³⁵ Within this broader dialectical frame, the websites report staff fear of ridicule, either in speaking about their patients’ deathbed visions at all or as evidence of an afterlife, which says something to me once again about the staff reticence I encountered. David Kessler’s websites also present the explosion of online commentary which points to the power of computer-mediated communication to draw posters to the Internet.

Dialectics on the Folk Web

I turn now to the vernacular web constructed by hospice, nursing home, hospital staff, volunteers, and other caregivers themselves concerning deathbed visions to see if and how these dialectics play out in the workplace and online.³⁶ I start with the assumption that these websites, consisting of commentary, blogs, chat rooms, forum discussions, YouTube videos, etc., do express these occupational folk cultures generally as well as on-the-ground attitudes towards deathbed visions particularly. The sheer number of sites gives me pause, however. To traverse this virtual cultural landscape in the space of an article section is not possible, but I turn toward two quite different websites, reached through a Google search, that are my supplemental treasure maps indicating the terrain.

Ask the Hospice Worker

“[Ask the Hospice Worker](#)” is a thread in one forum, now archived, of over 600,000 forums on different subjects administered and moderated through [The Straight Dope Message Board](#) website, designed to present and debate information as it has been “fighting ignorance since 1973,” according to its logo.³⁷ The original poster on the thread, a SDMB guest in his early thirties living in the Pacific Northwest, agreed to explain his job as a hospice worker because he believed it was not well understood by the general public, and he supported the goals of the SDMB online community. He noted in his 2012 opening post, “While most of my peers were flipping burgers, pumping gas or doing grunt work for construction crews, I was holding frail hands, cleaning human mess and, inevitably, performing post-mortem care,” ultimately as a certified nurse assistant in a home hospice program. He stated that he and most of his co-workers “keep our mouths shut regarding our jobs,” that his wife and children didn’t really know what he did for a living, and that it took him a long time to acknowledge what hospice work was.

Doing online what he could not do offline, he said that he would answer any questions posed³⁸ as fully as he could without breaking HIPAA rules protecting patients’ privacy.³⁹ Subsequent posters did ask him many things: What was the job like? How was palliative care managed? What did he think about physician-assisted suicide? Only one guest user asked him about deathbed visions:

Have you ever witnessed a dying person have Deathbed Visions? From what I've heard, they are common in the hospice environment. I don't know what your beliefs are as far as what happens when we die, but have you seen anything, well "spiritual" during the dying process.

The original poster responded in part:

Yes, deathbed visions are common. I'm fairly agnostic, but I've not found any explanations for these. I cannot even begin to explain the experience... [W]hen someone is in a deep coma and has been for several weeks, revives for an hour or two and sings hymns or has conversations with an empty room before passing away, the effect on an observer is haunting. I've seen

more that one of my co-workers leave the building during these visions; they couldn't handle what was happening.

His response is a microcosm of the individual and group dialectics operating across the profession. It shows that not all hospice workers see their patients' visions as positive signs of the afterlife, although many (if not most) hospice workers online and off do, but may see them with some ambivalence or uncertainty.

The original poster made it clear that hospice workers found it hard to speak to those outside the profession about their jobs in general; he didn't make it as clear if, how, or when they speak to each other, although his last post suggests that his occupational knowledge rests on his own job experience and on some discussion with his co-workers. He does corroborate experts' findings in the last section that hospice workers were reluctant to discuss these deathbed visions both on and off the job, yet he was able to speak online, which suggests that the stated goal of the Horizon Research Foundation's eQuestionnaire to expand the sample was a reasonable one. His posts also blur the binary between elite or institutional and folk in yet another way as his online position shows him to be an expert. He uses vernacular authority to shape the perspectives of other members within the online community (see Blank 2015; Howard 2008b; 2011; 2012; 2013). What this poster doesn't say, however, points me to conversations amplified on the web in the next site.

Allnurses.com

Allnurses.com is an extensive website designed as a "nursing community."⁴⁰ Its homepage logo—the name of the site, with three overlapping conversation bubbles—visually reinforces that it is a place "where nurses and nursing students talk." Despite links to articles and books by experts and to college and career opportunities, this social networking site is primarily a space where nurses can seek advice from peers in various discussion forums. "Deathbed vision" threads appear in three "General Nursing Discussions" ranging from 2006 to 2011, in two "Hospice Nursing Discussions" in 2010 and 2011, and in a 2011 "Nursing & Spirituality Discussion."⁴¹ The narratives embedded in these six threads are very like the deathbed visions accounts already discussed in this

essay. They are usually nurses' brief, first-person reports that may begin with an orientation including the type of facility, the role of the caretaker, or the patient's condition; then continue with a description of the patient's vision no other person can see as their complicating action; and often end with an evaluation including corroboration of the experience by a family or staff member, and/or a general statement or question of belief and care.⁴²

My analysis of participants' comments shows that forum users have debated the frequency, the etiology, and the meanings of deathbed visions their patients experience. Most agree with the original poster from the "[Ask the Hospice Worker](#)" website that patients' visions are common, although the number of experiences individual nurses have had or witnessed varies. In response to the query, "Have you taken care of any patients who've had any [deathbed visions]?" opening a 2006-2007 "General Nursing Discussion" DBV thread, one user's memorate has familiar patterns:

The first time I had a patient who was apparently having one was a lady who kept looking straight ahead at the wall & having conversations with someone named Mary that no one else could see. Come to find out from her adult son, Mary was his aunt who was deceased. The patient died a few days later.

(emphasis added)

Another user responded, "*Frequently*. In our palliative care, we see many patients who see relatives or visions before they pass." Another noted, "I have seen many patients in almost 25 years at the bedside, who have appeared to be conversing with invisible beings, and were at peace with this." Another noted, "I've seen this too many times to count."

Yet other participants were less certain. One wrote, "I've experienced it *a few times...* being a new nurse I didn't really think anything about it..." And another responded, "I don't know what to think about supposed 'deathbed visions.' I've been around a number of dying people and I've *never* seen anything from them like talking to people who we couldn't see." The last poster went on to give a counter- or anti-legendary account which contains its own dialectics (Dégh and Vázsonyi 1973). S/he once had a dying male patient who would tell nurses that he saw a man come into his room every night at the same time. While one of his or her colleagues "would freak out and run around telling everyone the angel of death was

visiting him and it would be anytime now," s/he noted that the patient himself "looked at us like we were crazy and said flatly, '*it's a shadow...*'"

The most hotly-debated issues, however, concerned the etiology of deathbed visions and their corresponding meanings for patients and for caregivers. In a 2010 "Hospice Nursing Discussion" DBV thread, "Do you believe in life after death?" the original poster asked: "What is your take on DBVs [deathbed visions] and the afterlife?" All nine respondents agreed that their patients' visions corroborated their own belief in life after death. One posted: "yes. I've seen too many patients speak to deceased loved ones. I've had patients tell me, 'there is an angel at the foot of my bed that tells me I'll be going soon...' These are not delirium patients." The last user's comment that his or her patients were not hallucinating hints at the debates that had erupted in other forum discussions.

The original poster in a 2008-2010 "General Nursing Discussion" DBV thread had asked what nurses had experienced and felt "regarding those ready to pass being able to see something just prior?" "In your opinion is there more after this?" s/he continued. The opposing opinions of two participants in the ensuing discussion made the dialectics starkly clear. The first commented, "I don't believe there is anything beyond. I've been around a lot of dying people and the visions can be explained by the dying brain shutting down..." The second responded, "I'm sorry to disagree, but you are out of touch, BIG TIME. I have been a hospice nurse for 15+ years and no matter what you think, do not EVER underestimate what a patient is going through at the time they are going to pass onto the other side..." And the first came back, "Well, *wanting* something to be true and getting annoyed when someone challenges it doesn't make it anymore true. I've seen death and dying in spades during my time as a LTC [long-term care] and private duty nurse..." Other participants duplicated and so corroborated their discussion, reflecting the materialist/dualist debate discussed in the previous sections.

Yet participants' comments also included a corollary debate about patients' "good" or "bad" deaths that was quite different from the presentation of only positive deathbed visions in the experts' sites reviewed—and, for the most part, in my own "Other Worlds" field research data as well. Those users who did discuss their patients' peaceful or frightening visions and subsequent deaths on this thread tended to frame them in the

relatively-standard dialectics of Christian eschatology in which “good” patients heard music, saw angels and other religious figures, loving relatives, and/or a beautiful place while “bad” patients encountered the Devil, demons, or spirits of those whom they had killed, and/or Hell itself. A hospice chaplain to whom I spoke, for example, noted that one patient he had counseled had appeared to “reach out his arms to his angel who had taken him home,” while another patient had told him before his death that “he went to an awful place where there was fire and dismembered bodies” (OWIIA.019).

Another exchange on this 2008-2010 “General Nursing Discussion” DBV thread disturbs on several levels. A posting nurse wrote, “I’ve seen numerous patients reaching out their hands in the direction of the sky. They seem to be wanting to go with someone but I don’t see anyone in the room...” but also commented, “I also had creepy experiences that I cannot forget. But I don’t want to scare anyone so I’ll just keep it to myself.” Another followed who did not keep it to him/herself:

I also have seen many of the beautiful peaceful scenes just described. But, (y’all knew it was coming, didn’t ya?) I saw one young man, early 20s, losing to cancer who woke up in the middle of the night SCREAMING at the top of his lungs “HE is coming to get me HE is coming to get me!!!!,” ...pointing to the crucifix on the wall and SCREAMING...

A third responded: “Yikes, that was pretty horrifying especially for him, I’d bet. I have read about some people who have had near-death experiences in which they recount hellish visions, I hope it’s the drugs in that case.”⁴³

Certainly this deathbed vision account is not the typical positive story, nor is it the less well-known but typical negative story either. Here, the patient, simply a too-young man dying before his time, appears to be terrified of death, of a strangely-avenging Christ coming for him, or of something else, but it is not possible to know for sure.⁴⁴ The last poster’s comment that s/he hoped this patient’s experience was a drug-induced hallucination and not a vision of the afterlife to come is a not uncommon one in which two dialectical positions intersect: a positive deathbed vision is seen as a spiritual experience while a negative one is seen not as hellish but as hallucinatory caused by medication. In any case, the patient suffered pain, anxiety, and terror before his death.

I see now that the hospice staff I interviewed for the “Other Worlds” study told me about primarily positive deathbed visions. A hospice nurse described a patient “reaching into air with hands turned upwards (palms up). When asked who he was talking to & reaching towards, pt. [patient] stated, ‘I’m talking to God’” (OWIIA.002). A hospice coordinator recalled that she had heard from a hospice nurse that “there was a gentleman who was active [actively dying]...he kind of drifted off a little bit, you know? And, when he had woken up, he had said, ‘Wow, those roses smell beautiful!’” (OWIIA.003). I presume that they were protecting me, perhaps themselves, from accounts of negative visions, another reason not to speak. Only two staff shared accounts that haunt me still in this regard. One spoke of a young woman, also a cancer patient, who saw a bright light at the end of her life, but told relatives that she was afraid of it and didn’t want to die and leave her small children (OWIIA.003). Another noted that she once had to push a dying patient in her wheelchair from room to room in the hospice because the patient saw her deceased mother always moving away from her and wanted to catch up (OWIIA.005). That these three patients were distressed when seeing Jesus, a white light, and a deceased mother respectively points to deathbed visions accounts that should be prototypically peaceful, but are terrifying (Bush 2012; Greyson and Bush 1992, 99-101).

Another corollary but important debate about deathbed visions emerged in the 2008-2010 “General Nursing Discussion” DBV thread as well, one in which participants questioned how the beliefs of caregivers compared to the beliefs of their patients and families, and how similarities or differences in belief impinged on hospice care. One poster’s response touches on all these issues. S/he opened by agreeing with a materialist medical model:

I believe in the power of the human brain’s ability to placate the dying patient by releasing a rush of neurotransmitters and endorphins as it dies, resulting in powerful and occasionally disturbing auditory and visual hallucinations in their last moments.

S/he continued, however, by recognizing that positive deathbed visions could have a comforting effect: “These... hallucinations and emotions along with the patients’ and families’ expectations of creed-dependent afterlives often bring comfort and joy to all

involved, and should not be discounted or denied.” Here the poster turned from the medical model of etiology to a hospice model of care which is to support patients spiritually and emotionally despite divergent scientific and religious beliefs.⁴⁵ “But that doesn’t mean I have to believe [deathbed visions] are supernatural in origin,” the poster concluded, disagreeing with other discussants who shared “patients’ and families’ expectations of creed-dependent afterlives.” I guess that this web user has wrestled with the dialectics widespread throughout hospice care, originally designed to offset the traditional medical model, and now more often incorporated within it in hospital settings (Siebold 1992). This DBV thread ended with: “We will likely have to agree to disagree on this point.”

David Kessler (2011) had presented these dialectics as debates between hospice workers and patients’ families who have witnessed deathbed visions that confirm the existence of the afterlife, on the one hand, and those individuals in the medical field and in the general public who haven’t had such experiences or discount them, on the other (159-62). These folk websites suggest, however, that these debates are more complex, more “messy,” and that they exist in various ways *within* hospice cultures as well, both online and off, a situation already noted by the professional researchers in the previous section, including Kessler himself, when they evaluated hospice staff and volunteers’ troubled attitudes toward deathbed visions.

What folklorist Robert McCarl has called “the canon of work technique,” that unwritten code that members of an occupation use as a standard for their on-the-job performances (1986, 71-72), is overlaid or fragmented here by contending concepts of belief and hospice nursing practices. A participant’s comment in the same “allnurses.com” 2008-2010 “General Nursing Discussion” DBV thread indicates two types of patient care that s/he practiced, the former a spiritual one s/he may or may not wish to speak of in the workplace, the latter a medical one that is standard: “Beyond the visions for the patients, I have felt a definite presence in the room with me as the patients pass. Of course, I have to check the pulse technically, but the feeling which I can’t describe otherwise has never steered me wrong.” A hospice nurse noted something similar: “I personally have had 3 pt [patients] come to me in dream state at exact time of death—before I received call to inform me—I knew already pt [patient] had passed on—felt presence in room when no one

but pt [patient] & myself in room" (OWIIA.012). The institutional and the vernacular are juxtaposed here (see Blank 2013b; 2015; Howard 2012; 2013).

A second participant in the same "General Nursing Discussion" DBV thread contrasts his/her silence in either the workplace or other social situations to web discussion on end-of-life experiences once again:

Being a hospice nurse, I too have seen/shared experiences that I'll bring to my grave. [O]therwise, in this society, I'd be committed. [S]o while there is no doubt in my mind re[:] an afterlife, I strongly believe that [posters] have every right to believe what they do, and be able to express it w/o condemnation.

These posts confirm for me that the "folk realm...represents a participatory process that some posters refer to as the democratic or open web" (Blank 2009, 23)⁴⁶ in contrast to the more structured elite sites discussed in the previous section and to the more structured workplace that has a hierarchy of job descriptions in both medical and administrative lines.

I recognize that field researchers in the medical field (as in others) are often aligned with management and with experts in general despite their best efforts. I received permission from the hospice CEO and managing team to conduct research with their staff and volunteers, as I needed to do for IRB compliance, but the management stipulation to interview staff onsite may have had some inhibiting effects. This alignment may have made it difficult for staff to speak openly if their perceptions and interpretations of their patients' deathbed visions contravened specific facilities' patient care guidelines (especially HIPAA rules), or, alternatively, might be open to ridicule in other medical and social contexts.⁴⁷ In contrast, users on the open web can share—and contest—information horizontally or laterally across similar nursing positions in a range of facilities whose specific names and locations are kept confidential in the discussion threads.

Standing on "the thin place" between this world and the next, between traditional fieldwork and the folk web, I now see more answers to my question "why" that prompted this article. Website users in hospice, hospital, and nursing home forums can "agree to disagree" on deathbed phenomena in cyberspace in ways that do "virtualize and mimic the dynamics" of the legend process (Blank 2012, 6; see also Blank 2007), its dialectics long

noted as a defining characteristic of the folk genre.⁴⁸ Because some staff chose not to, or cannot, speak of these end-of-life experiences in the work place and/or to an ethnographer, the open web somewhat paradoxically allows them a venue for communicative practices not always possible in specific real-life contexts.⁴⁹

Revelations

In threading my way through deathbed vision discussions on “allnurses.com,” I stumbled across posts that opened up vistas I had not expected on my virtual journey. Another sort of double tracking emerged. The first track concerns a genre question: how *do* deathbed vision narratives fit in the analog and digital realms of storytelling? The second track concerns an ethnographic question: What *is* the moral space of the ethnographer in both these realms?

Ghost Stories

In 2011, an “allnurses.com” guest poster asked the same questions about the meaning of deathbed visions in two DBV threads, one in a “Hospice Nursing Discussion” and the other in a “Nursing & Spirituality Discussion.” S/he wondered whether there was an afterlife or not, and if his or her recently-deceased father would find peace and joy there, having been an angry man who was an agnostic. S/he thought that hospice nurses could give answers that readings and discussions with others in his or her church had not: “...I’d like to hear real experiences from real hospice nurses on death bed visions and experiences.” Then, first in one post and then in another, s/he continued with questions that caught me off guard:

And why are there so many ghost stories in allnurses? Could these be souls that didn’t make it to the light? Or could they be real demons? [...] And what about the huge ghost stories thread? What do you think is responsible for ghosts? Evil spirits, demons, lost souls? And how could a soul get lost?

Although I have built a case here that deathbed vision narratives are, or are like, supernatural legends or memorates, both in their theme of “the return of the dead” and in the dialectics of their performance online and off, and can be examined within that

theoretical frame, I had not expected web users to make similar associations. I found myself, somewhat surprisingly, uncomfortable with the connections that brought me back full circle to the traditional ghosts and revenants with which I began this essay (see pp. 6 herein). I turned toward “the huge ghost stories thread” titled “What’s your best nursing ghost story?” in a “General Nursing Discussion.” Something like a lost soul myself, I wandered through the complex web of stories participants have shared since 2000 about their patients’ and family members’ deathbed visions, near-death experiences, premonitions of death, haunted hospice and hospital rooms or buildings, signs deceased patients gave their caregivers through flashing lights and call bells ringing, and more.

Users here seem less interested in questioning the meanings of these on-the-job experiences than in the stories and in storytelling itself. One noted, after telling a story of obstetric nurses’ smelling the scent of roses in a labor and delivery unit of a hospital when a mother or her baby was having difficulties, and seeing rose petals fall if the mother or baby died, “I do have other stories that are creepier than these,” and another responded, “That was a good one, please tell more.” Another said, “I haven’t actually seen any ghost but my unit has some ghost stories...” Another reported that s/he had “heard older nurses telling their stories about ghosts...” In a certain way, this thread, detailing nurses’ extensive storytelling online and off, confirms nurses’ freedom to speak on the web, but contradicts my sense of their offline silence developed in the preceding sections so needs to be addressed, if not explained.

Perhaps most participants see deathbed vision narratives and ghost stories as interchangeable or at least related by default as they have posted on this thread. Some, however, seem to see their deathbed visions (DBV) accounts as similar to but different from ghost stories. One began, “Not so much a ghost story, but a story about when my Mom died a year ago,” before detailing the succession of deceased family members to whom the dying woman spoke. Another was uncertain, noting, “I don’t know if this qualifies as a ghost story but here it is,” before posting his or her moving experience of feeling a cold chill every day at 12:15 p.m. for a week before a young patient died in his or her arms at that time.

I am of two minds about the place of deathbed vision narratives in ghost story classifications myself. The similarity of story theme and communication style I focused on

earlier can be undercut by what I also see as the different shapes of the narratives and their different contexts. Deathbed visions accounts presented so far do have their own shapes as noted earlier (see pp. 19 in this essay), set within the context of caretakers discussing their patients' numinous end-of-life experiences. Yet some DBV narratives do take on shapes of the classic ghost story, either in their orientation sections, in their complicating actions or in their concluding evaluations. A nurse, participating in a DBV thread in a 2006-2007 "General Nursing Discussion," for example, posted an account of a dying patient telling staff, when they asked her to whom she was talking, that it was a little girl who kept coming to see her. The nurse concluded, "We told her niece about it the next morning when she came to visit, and she said several of their family members have also talked of a little girl dressed in white coming to see them soon before death." The post's evaluative conclusion suggests a family legend and is a widespread ghostly motif (E422.4.4 (a) "Female revenant in white clothing"; E425.1.1 "Revenant as lady in white").

Elderly patients seeing children whom others cannot see has been reported on all the deathbed visions and ghost story threads I examined on [allnurses.com](#) as well as in an ethnographic study of nursing homes discussed earlier (Brayne 2008, 199-200) and in my own "Other Worlds" research. I briefly compare texts of two nurses' accounts, one posted online in a DBV thread in the 2006-2007 "General Nursing Discussion," and the other told to me during an interview (OWIIA.020) that further illustrate generic complexities and intersections in these dual worlds of storytelling:

ORIENTATION

From poster on [allnurses.com](#):

I worked for five years in a high care aged care facility that used to be an old county hospital—the building would have been close to 90 years old.

From interviewee:

I was told that [the nursing home] used to be a Catholic children's hospital ward before it was a nursing home...

Both nurses begin with the legendary equivalent of "It was a dark and stormy night," noting that their respective nursing homes were superimposed over past hospitals, a staple of ghostly legends and horror tales, that sets the stage for the action to follow.

COMPLICATING ACTION

From poster on allnurses.com:

One evening a lady who was in the early stages of dementia refused to eat all of her dinner, telling me that she had to keep some food aside to feed the two children that had come into her room the night before. I didn't think too much of this thinking that it must have been the dementia setting in. The next night she did the same thing again and left half of her meal for the kids, except this time she was really cranky complaining that the 'children' had been naughty and kept her awake for half of the night.

Two rooms down a frail resident who didn't have dementia was in a real state and scared to have the light off because the night before 2 kids who were covered in bandages had come into her room during the night and stood staring at her while she lay in bed.

Both nurses' remarkably similar descriptions of their respective patients' encounters with ghostly children shift the DBV accounts' focus from the more usual "take away" function of patients' deceased loved ones to the antics of children who may be both signs of impending death and residues of earlier tragedies, ghost story themes as well.

EVALUATION

From poster on allnurses.com:

By this time I was getting goose bumps and mentioned something to one of the other nurses who'd worked [there] a lot longer than me and wasn't at all surprised at what I'd told her. The nurse I was talking to said that apparently back in the early 70's a family had crashed their car, the parents had died instantly and their 2 children had been badly burned and brought to the nursing home when it was still a hospital. The kids ended up dying and over the years different residents with and without dementia had reported seeing them.

From interviewee:

But a couple of the patients that I had worked with would stop wanting to come to activities, and just stopped wanting to go to dinner, and things like that. And when you would ask them, you know, "Why don't you want to go?" they would say, "Well, I'm busy. I have to watch these kids." And, of course, I would ask them, "What kids?" because I could not see the children. It was a patient who—she was the sweetest old lady I'd ever seen—but she only had one leg. I'm not sure, I can't really remember what happened, but one day we found her out of bed, and she said she had fallen. And we asked her, you know, "Why did you try to get out of bed? You know you only have one leg at that. You need help." And she said, "Well, those kids were just runnin' around and I just, I had to go get 'em."

From interviewee:

Well, just from hearing other people talk; it wasn't just my floor. On different floors you would hear different things. The nurses would claim that they would hear babies cry, or just kind of, I guess, moans and groans that people would expect to hear or something.

Both nurses conclude their accounts with summaries of nurses “talking story” to each other in real and virtual time. In the online nurse’s account, a senior nurse gives the poster the back story to the present haunting, familiar in ghost story telling and legend tripping, which corroboration suggests that the poster moved from assuming that the children are hallucinations of elderly persons suffering from different stages of dementia to believing they may be of supernatural origin. The nurse I interviewed sets her account within the general framework of nurses talking on different floors, making references to the widespread legend of “the crying baby” and “moans and groans” associated with ghostly encounters (E402.1.1.3 “Ghost cries and screams”). Her own personal experience narrative corroborates the older nurses’ stories: “But one night I was in the hallway and I saw a balloon, and then all of a sudden the balloon just like shot down the hallway like a little kid was running with the balloon...”

Ghost story comparisons suggest that there are a number of deathbed visions narrative styles ranging from the most minimal account to a hybrid DBV/ghost story to full-blown legend performance, dependent on contexts closer to or further removed from nurses’ dying patients. In the “allnurses.com” 2011 “Nursing & Spirituality Discussion” DBV thread, one participant wrote, “I hesitate to share any visions that my patients have had, simply because those are the most intimate moments of their lives... I respect and honor that privacy.” Other staff chose not to speak in the workplace or to an ethnographer but chose to speak online as evidenced in “Ask the Hospice Worker” and “allnurses.com” sites in the last section. Hospice staff and volunteers, in particular, experience specific on-the-job stresses, not the least of which is the loss of their patients, which may make it difficult to “talk story” in real time.⁵⁰ Still others shared stories with co-workers online and off that have the patina of twice-told tales as evidenced in this subsection on ghost stories. Staff ghost stories may be part of new members’ introduction to their respective facility’s culture. When patients’ deaths are not immediately imminent, as is true in nursing homes for the most part, storytelling seems to flower for its own sake in traditional and virtual worlds.

Ethnographies

In 2011, an updated deathbed visions thread opened in a “General Nursing Discussion” on “allnurses.com.” The original poster had read all previous posts and noted, “It was very intriguing hearing all these deathbed vision stories from hospice nurses’ point of view.” S/he started a new thread “for fellow new members and old ones too to post their experiences with their patients having deathbed visions and passing on to the next life.” S/he concluded with a request, “Whatever *story* you have, new or old, please don’t hesitate to post it here” (emphasis added). When responders tended to post opinions, not buttressed by specific stories, the original poster requested again, “Thanks guys for all the responses so far. I read them all and I’m intrigued. But what I’m looking for is more hospice nurse *stories* about your patients” (emphasis added). His or her double request prompted another participant to comment:

I’m curious. You just joined today and your first post is requesting info about very specific type situations. Are you gathering these stories to include in some sort of publication or project? It’s a good topic, just makes me wonder whether there isn’t more to why you are asking, that’s all.

The original poster did not respond.

I had a double rush of feelings. Because I had not contacted participants online or off as this possible virtual ethnographer had done without attribution, I felt virtuous, on the one hand. But since the original poster and I were essentially mining the same data base for hospice workers’ and nurses’ stories without their knowledge, s/he more actively and I more passively, I felt an associated guilt, on the other hand. I imagined my discussion with the astute user who asked if a publication was forthcoming, explaining that I did, indeed, have my university IRB’s permission to examine archived material online without consent needed as the archived posts were publically published, and I was not conducting online participant observation defined as research, but I wondered if I were protesting too strongly.

The above exchange makes me mindful of folklorist Montana Miller’s cogent plea for ethnographers to consider evolving online ethical guidelines as seriously as they have

offline ones (2012). I am particularly struck by her discussion of “oral expression and archived text, tangled in the new ethics of the web” (215-17), because it applies directly to my own cyberethnography of archived forums. The forums, indeed public in the sense presented above, also do have a private quality because they reveal information that hospice and hospital staff chose not to speak of in the workplace or to an ethnographer. I defined them as “folk” or “vernacular” webs for that very reason. The stories embedded in the discussion threads can be seen as both public records of legendary texts and as examples of what Miller calls “a new form of orality or folk speech” (216) on the web. If the latter designation predominates in future discussions, should I attempt to obtain consent from those posters even though I do not need to do so? Angela Cora Garcia et al. (2009) confirms that the ethical landscape for the use of online archival data is “not yet clear” because of the complexities of “public” and “private” designations (74-75).

Lurking on the folk web can yield incredible information for the ethnographer, information that is not necessarily accessible in the more formal face-to-face interviewing situation, but is it all right to do so? I did try to protect the privacy and anonymity of forum users by not using their addresses or fully quoting their posts, as hard as it is for me not to use full verbatim texts as I was trained to do (Garcia et al. 2009, 76-77; Miller 2012, 221-23). If I, too, had opened up a thread as a guest poster on “Ask the Hospice Worker” or on “allnurses.com,” once I had IRB approval for interactive research, would I have been a poseur? The consensus seems to be that there is not presently a consensus on how best to represent oneself as a researcher to online communities that is both practical and ethical (Garcia et al. 2009, 76).

My article falls under what Garcia et al. (2009) categorizes as one with multimodal social worlds as research settings that call for both traditional fieldwork and computer-mediated communication (55-56). In fact, that bridge between analog and digital worlds is its *raison d'être*.⁵¹ For that reason, I look briefly at issues of ethnographic transparency, online and off. A staff member at the hospice where I did traditional fieldwork asked me point-blank what an English professor was doing there, rather than a healthcare professional—a good question.⁵² I did not reveal that I was a folklorist, but I did present my

interest in storytelling as part of a medicinal and narrative approach conducted by humanists and social scientists.⁵³ I would do the same in an online setting.

If that staff member had asked me what my own position on deathbed visions was, I would have said that I was an ex-Catholic, interested in spiritual issues and right living, but probably closer to the agnostic positions of some of the hospice workers quoted here at the present time. I was interested in hearing what people had to say about deathbed visions and recognized that I was working through my own fear of death in doing so. In fact, I did say that in some of the interview situations at the hospice when interviewees asked, but not otherwise. I would say the same in an online setting.

If that staff member had asked me what conclusions I would publish as an outgrowth of my qualitative field research there, I would not be able to answer precisely—yet. Folklorist and sociologist Gary Alan Fine has noted the tension between the idea that “research subjects... have a right to know what they are getting themselves into” and the reality that “ethnographers do not know what they are looking for until they have found it” (1994, 4-5). As an ethnographer, I tend toward just such grounded theory, yet recognize that research subjects, online or off, deserve answers. In the last section below, I work toward some of those answers, because my initial foray into cyberspace convinces me of the richness of a joint enterprise in exploring questions about life and death, traditionally and virtually, in as sensitive a way as possible (see Blank and Howard 2013).

Conclusions

I position my “Other Worlds” project in the Midwestern hospice differently than I did before this journey straddling real and virtual space. My research had been localized in a specific geographical setting, what media and cultural specialist Andreas Wittel would call “the field” in a traditional sense (2000, 1-2), although I practiced what anthropologists Akhil Gupta and James Ferguson defined as non-classical fieldwork, not leaving my home base to do research in a remote geographical and cultural area but staying in the urban location where I already lived and visiting the local research sites intermittently over some years (1997, 19-32).⁵⁴ I see the data created from qualitative face-to-face interviews with willing staff, questionnaires completed and journal entries as deep but limited. These

“intimate ethnographies” (Langlois 2008, 187-89) give me a contextual base to learn what brought staff into hospice care, how they dealt with their patients’ deathbed visions, and how they interpreted them. They are vertical cultural markers.

Yet I see that I have moved “from the field to the Net” (Wittel 2000, 3-5) when I recognized that my localized project was embedded in discussions far broader than my own in sites that have the advantage of creating far more data, graphed through time and space, not available in any other format, despite possible issues with anonymity, deceptive identity, and a certain a-contextualization (Garcia et al. 2009, 68-70). They are horizontal cross-cultural markers. My review of the elite and the folk webs on deathbed visions (which have merged in a number of ways for me as I traversed them) gives me a sense of the importance of networking for shared references, resources, and data checks across all lines of demarcation.

I believe, for example, that deathbed vision websites on what I’ve called the elite web, despite their agendas, do fill a gap in the anthropological, folkloristic, and medical literature on medicine and narrative generally, and on hospice and narrative in particular, which latter sources do not usually focus on health issues and the supernatural to my knowledge.⁵⁵ The exceptions prove the rule.⁵⁶ StoryCorps’ recent development of its **StoryCorps Legacy Project** which pairs interviewers with palliative care and hospice facilities may move in this direction, although the interviews I have listened to online to date are extensions of the patient’s life review.

I also believe that discussions on the folk web expand the concept of legend dialectics, a process that I found submerged in the fieldwork in the everyday world of the hospice where “Other Worlds” research subjects shared mostly positive experiences with me. This research for this essay confirms what Trevor J. Blank has called the oxymoron of traditional oral texts and performances emerging through technology (2012, 6; see also Blank 2013a; 2015; Buccitelli 2012), here in an enhanced way that did not happen in the questionnaire process or in face-to-face interviews in my “Other Worlds” field project. I, therefore, conclude that traditional and virtual ethnography together can contribute to a more holistic picture of deathbed visions narrative, richer than each modality of accessing

"return of the dead" stories might yield alone, and whose complementary approaches might compensate for the flaws in each methodology.

My virtual field research itself moved me, albeit not very far, "beyond the field to the Internet" (Wittel 2000, 6). I remain a digital immigrant after all, but a more informed one. I can now appreciate digital natives, those for whom online social media are even more intrinsic parts of their lives, whether participants or researchers on the Internet. I have been particularly touched by a young man's posthumous online video in which he presents his near-death experiences and his questions about the afterlife for whoever clicks [on his YouTube site](#). Austin (TX) blogger Ben Breedlove's presentation haunts the Internet much as Pennsylvania State Treasurer R. Budd Dwyer's televised suicide does long after his death (Bronner 2009, 40-56), but that is another story.

For now, I am content to close this meditation on story gathering with a quote from a hospice nurse I interviewed in the "Other Worlds" project. Her statement gives researchers, older and younger, good reasons for continuing their work, online and off, while also giving more good reasons why hospice staff aren't always talking. They simply don't have the time:

I am glad that you are collecting this information... Lots of people in hospice... would write that kind of book if we would just get together and take the time. A couple of people have given us [blank] books that we should write down the stories as they happen but we just have not done it. I don't know how to integrate it into hospice work because it would be meaningful to a lot of people, but you know you just get wound up in it; it's tiring, it's exhausting, it's gratifying, it's genuine, it's intense. (OWIIA: 014)

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Notes

¹ This article is a development of a paper presented at the International Society for Contemporary Legend Research's Perspectives in Contemporary Legend Conference in Harrisburg, PA, May 26, 2011.

² See Blank (2007; 2009; 2012; 2013a; 2013b); Blank and Howard (2013); Ellis (2002); Foote (2007); Frank, Russell (2011); Hine (2000); Howard (2008a; 2009; 2011); Kinsella (2011), for example.

³ These are overlapping terms, with slightly-different meanings depending on the field of study, which I use interchangeably here.

⁴ The title of the full project, “Other Worlds”: An Ethnographic Study of Personal Accounts of the Return of the Dead and Other Mystical Experiences in Health-Related Contexts” (IRB #069403B3B), is shortened to “Other Worlds” in this essay. See Appendix A for Part IIA Research Informed Consent Form and Appendix B for IIA Questionnaire for Hospital and Hospice Staff and Volunteers Form referred to in this essay.

⁵ I have not interviewed terminally-ill patients because they are classed as vulnerable subjects in IRB guidelines, and I am not a trained health professional.

⁶ “The Return of the Dead” is a general theme in supernatural legendary around which narrative motifs cluster. Folklorist Louis C. Jones writes: “It would be an endless task to present the wide variety of reasons why the dead return, but perhaps a little sampling will give some idea. After examining hundreds of accounts of ghosts, it seems to me that these reasons fall roughly into five categories: they come back to re-enact their own deaths; to complete unfinished business; to re-engage in what were their normal pursuits when they were alive; to protest or punish; or, finally, to warn, console, inform, guard, or reward the

living" (1977 [1959], 19). Motif category E200-E599 Ghosts and Other Revenants contains both E200-E299 Malevolent return from the dead and E300-E399 Friendly return from the dead. See Thompson (1960).

⁷ The "Other Worlds" book-length project is based on three fieldwork situations: Part I questionnaires and/or interviews with a general convenience population willing to speak on their mystical health experiences (30 participants), Part IIA questionnaires and/or interviews with hospice, hospital, and nursing home staff (26 participants), and Part IIB questionnaires and/or interviews with bereavement and grief support groups (which did not materialize in the group settings but individually). Seven "Other Worlds" field journals and other ethnographers' and students' archived data are additional primary source material.

⁸ The list includes, but is not limited to: spiritualists, mediums, psychics, psychical researchers, parapsychologists, near-death researchers, folklorists, anthropologists, sociologists, communications specialists, ministers, religious studies scholars, psychologists, psychiatrists, bereavement counselors, death and dying specialists, hospice and palliative care doctors and nurses, social workers, cardiologists, neuroscientists, medical humanists, and medical ethnographers among them. Although I cannot address all their research here, I will reference specific works within the contexts of relevant discussions throughout this essay.

⁹ See Bennett (1999) and Rees (1971), for example.

¹⁰ See Fenwick and Fenwick (1997); Holden et al. (2009); Moody (2001[1975]); Moody and Perry (1993); Ring (2006), for example.

¹¹ David J. Hufford notes that "death omens and deathbed visions may be a part of the NDE class or they may constitute a separate class" of core experiences (1995, 35). A 2012 bioethics forum held at the University of Wisconsin at Madison's BioPharmaceutical Technology Center Institute, presented deathbed visions as one kind of NDE experiences, for example. See: <http://www.btcp.org/bioethics/default.html>.

¹² See Barrett (1986 [1926]); Curtis (2012); Kessler (2011); Kübler-Ross (1991; 1999); Mendoza (2008); Osis and Haraldsson (1997 [1977]), for example.

¹³ Staff includes doctors, nurses, certified nurse assistants, social workers, ministers, spiritual counselors, psychologists, administrators, managers, etc. working in facilities caring for terminally-ill patients.

¹⁴ There are over 400,000 results as of this writing.

¹⁵ Code refers to the twelfth questionnaire and/or interview transcript of "Other Worlds" Project, Part IIA (see Appendices A and B). Although I have not been able to check this

systematically, I believe that hospice nurses completed the questionnaires as if they were patients' (pt) charts.

¹⁶ Many researchers of deathbed visions refer to Barrett's (1986[1926]) seminal work. I do so also because of the ethnographic quality of his reporting of this moving case. Like many present NDE researchers, he wished to put the study of these phenomena on a scientific basis so founded The Society of Psychical Research in 1892.

¹⁷ Religious studies scholar Carol Zaleski brought digital and spiritual "other worlds" together for me when she thanked the staff of the Harvard Arts & Sciences Computer Services for helping her find her way "in the labyrinthine other world of electronic text processing" in her acknowledgements for *Otherworld Journeys: Accounts of Near-Death Experience in Medieval and Modern Times* (1987, v). When I read her thanks years later, the convergence made sense, and reminded me of folklorist Linda Dégh's exhortation that "researchers of the legend must try to enter the labyrinth of the alternative communicative vehicles" that legend tellers use now, including the Internet, for fuller understanding of the genre and its meanings in modern life (2001, 304).

¹⁸ See Blank (2012; 2013b; 2015) and Howard (2005; 2008a; 2012; 2013) for fuller discussions of the institutional and vernacular uses of websites for hybridized folk communication that I find at the heart of my essay's double consciousness.

¹⁹ I selected these three websites to begin my digital ethnographic journey because they were among the first listed in the initial Google search results, which I assumed signaled their particular relevance to my area of interest, and because I knew something of related analog studies for comparison and contrast.

²⁰ See Foote (2007) and Garcia et al. (2009, 62-64) for additional insight into iconic memes in digital culture.

²¹ Note that Barbato (1999) connects deathbed visions (DBV) and bereavement accounts (ADC) here for grieving persons.

²² I used variations of the Barbato team's questionnaire, "Survey of Unusual Happenings and Experiences at or around the Time of Death," with permission, in my "Other Worlds" field research.

²³ Variously called "the mind/body problem" or the "materialist/dualist question," the debate that runs through this essay centers on the question whether the mind is part of the brain, so that consciousness does not survive a person's physical death (materialist) or whether the mind and the brain are separate (dual) so that consciousness may survive a person's physical death (non-materialist).

²⁴ See Fenwick and Fenwick (1997); Greyson and Bush (1992); Parnia (2014); Roach (2005).

²⁵ The website's homepage has frequently updated links to recent cognitive studies, including the major international and interdisciplinary [Human Consciousness Project the Foundation sponsors](#), designed to explore what had been "traditionally considered a matter for philosophical debate," but through "advancements in modern science and in particular the science of resuscitation" is now open to scientific analysis." The [AWARE \(AWAreness during REsuscitation\) study](#), in particular, is a long-term program, the first sponsored by the Human Consciousness Project, which aims to study the relationship between mind, consciousness, and brain in patients who undergo cardiac arrest and clinical death. The results of the AWARE study are not yet posted on the site as of this writing.

²⁶ Deathbed visions are included in the NDE category on this site.

²⁷ All quotations concerning the "Deathbed Visions eQuestionnaire" come from online statements no longer available.

²⁸ Deathbed visions (DBV) are a part of the broader category of Deathbed Phenomena (DBP).

²⁹ See also Cole (1992) and Rodriguez (2009) for studies of hospice narratives about patients' choosing or knowing time of death.

³⁰ Discussion of animals, insects, and birds occurred in my "Other Worlds" field research in bereavement narratives as the recently-deceased returning in other life forms, not in deathbed visions. Staff did discuss spectral children, however, which will be a focus later in this article.

³¹ There are no discussions of cold spots by hospice staff or families in my research notes, but discussion of air movement or electricity or energy at the moment of a person's death was noted in several instances.

³² See Kübler-Ross (2000 [1971]).

³³ In *Visions*'s "Epilogue," Kessler refers to the Camden Palliative Care study's finding of hospice and hospital staff feeling ill-prepared for and uncertain how to deal with their patients' deathbed visions (152). He reiterates the fact that medical personnel, patients and their families are reluctant to speak of these experiences for fear of ridicule, and that a fuller understanding of the dying process would bring peace for all at the end of life (152-55).

³⁴ See Blank (2013a; 2013b; 2015); Buccitelli (2012); Howard (2005; 2008a; 2008b; 2012; 2013).

³⁵Recent examples of the dialectics include best-selling works by Alexander (2012); Burpo and Vincent (2010); Parnia (2014) (dualist), and Sachs (2012) (materialist). A March 26, 2013 episode, “Is There Life after Death?” on the Science Channel’s *Through the Wormhole with Morgan Freeman* is framed within these dialectics.

³⁶ Like David Kessler (2011), I have made a choice not to discuss sites constructed by mediums and psychics at the present time, but these sites should be examined and evaluated at some point.

³⁷ The archived posts on this thread remain online as of this writing. I use verbatim quotations sparingly and conversation summary to protect posters if possible.

³⁸ To clarify his openness and invitation for communal discourse, the poster included the phrase “Ask me anything,” his spelling out of the more usual acronym AMA, in his initial comments.

³⁹ The Health Insurance Portability and Accountability Act (HIPAA) is the federal law enacted in 1996 to protect patients’ personal medical information through mandating medical facilities’ compliance with its rules.

⁴⁰ Brian Short, Allnurses.com Inc.’s CEO and only full-time employee as of 2012, quit his job as a critical-care nurse at Hennepin County (MN) Medical Center to devote full time to his social networking site that has grown to over three million users monthly (see Grayson 2012).

⁴¹ Although all archived forum thread locations are numbered for users’ ease of access in this website, I refrain from listing them, and also use verbatim quotations sparingly and conversation summary to protect participants if possible. The website refers to forums as “discussions,” and I follow that terminology.

⁴² See Labov and Waletzky (1967, 32-37) for their early presentation of the formal features of personal experience narratives I draw on here and later in this essay.

⁴³ See folklorist Yanna Lambrinidou’s discussion of the deathbed visions of a patient who saw the comforting vision of her deceased mother and also heard threatening voices of those she thought were trying to kill her as quoted in Barnard et al. (2000, 97-119, 418). See also Bush (2012), Greyson and Bush (1992); Rawlings (1993) and Roach (2005).

⁴⁴ This account is more in line with Osis and Haraldsson’s (1997[1977] findings that younger Hindu patients were often frightened by Yamdoot (Yama), a Hindu god of death, coming for them.

⁴⁵ This mediating role is in line with the advice given to caretakers by hospice nurses Maggie Callanan and Patricia Kelley (1992) in their influential guide, *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. Callanan and Kelley advise in their chapter, “Being in the Presence of Someone Not Alive,” that hospice workers listen to their patients and recognize that, whatever their own beliefs, their patients do not feel alone when these visions occur, and that is a good thing whatever their provenance (97).

⁴⁶ See also Blank (2013b); Buccitelli (2012); Howard (2008b).

⁴⁷ See the next section on “ethnographies” for further discussion of inhibiting factors in traditional field interviews.

⁴⁸ See Bennett (1999, 115-37); Dégh (2001); Dégh and Vázsonyi (1973); Ellis (2002); Goldstein (2007, 60-78); Langlois (2005); Tucker (2009).

⁴⁹ I have used Trevor J. Blank’s statement that online communication can be distinct from face-to-face communication, although related, so it is “not always entirely transferable or functionally replicable” (2012, 7) to my own purposes here.

⁵⁰ Hospice workers experience this loss universally by the very nature of their job, as often do related medical personnel such as paramedics and hospital emergency room staff. Interestingly enough, the “Ask the Hospice Worker” original poster criticized paramedics as paramedics criticized firefighters and hospital emergency room personnel for their incompetence in aiding patients at death’s door (Tangherlini 1998, 3-31), and as one poster in “allnurses.com” indirectly criticized doctors who do not interact with their patients as fully as nurses do.

⁵¹ I believe that I am discovering the hybridization of folklore, “the blending of analog and digital forms of folklore and vernacular expression in the course of their dissemination and enactment” (Blank 2013a, 116), in spite of myself.

⁵² I do not have the healthcare credentials that the research teams outlined earlier in this essay had, or those of folklorists David J. Hufford, former director of Medical Humanities at the Hershey School of Medicine at Pennsylvania State University (1982; 1995); Yanna Lambrinidou, who worked with a hospice team, and actually moved into palliative care herself (Barnard et al. 2000); or of Erika Brady (1987), who was a hospice chaplain before entering the field, for example.

⁵³ See Barnard et al. (2000); Frank, Arthur (1997); Gelfand et al. (2005); Hufford (1982); Hunter (1991), for example.

⁵⁴ Gupta and Ferguson's (1997) critique of "classic field science" is a prelude to virtual ethnography in a sense because in it they advocated a loosening of ethnographers' focus on a single geographical and cultural location.

⁵⁵ See Barnard et al. (2000); Frank, Arthur (1997); Gelfand et al. (2005); Goldstein (2004); Hunter (1991); Kitta (2011); Mattingly (2000); Parker (2007); Tangherlini (1998); Zeitlin and Harlow (2001), for example.

⁵⁶ See Brady (1988; 2001); Cole (1992); Hufford (1982; 1995); Mendoza (2008); Rodriguez (2009), for example.

References

- Alexander, Eben. 2012. *Proof of Heaven: A Neurosurgeon's Journey into the Afterlife*. New York: Simon & Schuster Paperbacks.
- Barbato, Michael. 2002. *Caring for the Dying*. Sydney, Australia: McGraw-Hill Australia.
- _____. 2009. *Reflections of a Setting Sun: Healing Experiences around Death*.
- Barbato, Michael, Cathy Blunden, Kerry Reid, Harvey Irwin, and Paul Rodriguez. 1999. "Parapsychological Phenomena Near the Time of Death." *Journal of Palliative Care* 15, no. 2: 30-37.
- Barnard, David, Anna Towers, Patricia Boston, and Yanna Lambrinidou. 2000. *Crossing Over: Narratives of Palliative Care*. New York: Oxford University Press.
- Barrett, Sir William. 1986 [1926]. *Death-Bed Visions: The Psychical Experiences of the Dying*. The Colin Wilson Library of the Paranormal. Wellingborough, Northamptonshire, England: The Aquarian Press.
- Bennett, Gillian. 1999. *Alas, Poor Ghost! Traditions of Belief in Story and Discourse*. Logan: Utah State University Press.
- Blank, Trevor J. 2007. "Examining the Transmission of Urban Legends: Making the Case for Folklore Fieldwork on the Internet." *Folklore Forum* 37, no. 1: 15-26.
<https://scholarworks.iu.edu/dspace/handle/2022/3231>.
- _____. 2009. "Toward a Conceptual Framework for the Study of Folklore and the Internet." In *Folklore and the Internet: Vernacular Expression in a Digital World*, ed. Trevor J. Blank, 1-20. Logan: Utah State University Press.

- _____. 2012. "Pattern in the Virtual Folk Culture of Computer-Mediated Communication." In *Folk Culture in the Digital Age: The Emergent Dynamics of Human Interaction*, ed. Trevor J. Blank, 1-24. Logan: Utah State University Press.
- _____. 2013a. *The Last Laugh: Folk Humor, Celebrity Culture and Mass-Mediated Disasters in the Digital Age*. Madison: University of Wisconsin Press.
- _____. 2013b. "Hybridizing Folk Culture: Toward a Theory of New Media and Vernacular Discourse." *Western Folklore* 72, no. 2: 105-30.
- _____. 2015. "Faux Your Entertainment: Amazon.com Product Reviews as a Locus of Digital Performance." *Journal of American Folklore*, forthcoming.
- _____, ed. 2009. *Folklore and the Internet: Vernacular Expression in a Digital World*. Logan: Utah State University Press.
- _____, ed. 2012. *Folk Culture in the Digital Age: The Emergent Dynamics of Human Interaction*. Logan: Utah State University Press.
- _____, and Robert Glen Howard, eds. 2013. *Tradition in the Twenty-First Century: Locating the Role of the Past in the Present*. Boulder: University Press of Colorado.
- Brady, Erika. 1988. "The 'Beau Geste': Shaping Private Rituals of Grief." In *1987 Folklife Annual: Publication for the American Folklife Center*, eds. Alan Jabbour and James Borden. Washington, D.C.: Library of Congress.
- _____, ed. 2001. *Healing Logics: Culture and Medicine in Modern Health Belief Systems*. Logan: Utah State University Press.
- Brayne, Sue, Chris Farnham, and Peter Fenwick. 2006. "Deathbed Phenomena and Their Effect on a Palliative Care Team: A Pilot Study." *American Journal of Hospice and Palliative Medicine* 23, no. 17: 17-24. <http://ajh.sagepub.com/content/23/1/17>.
- Brayne, Sue, Hilary Lovelace, and Peter Fenwick. 2008. "End-of-Life Experiences and the Dying Process in a Gloucestershire Nursing Home as Reported by Nurses and Care Assistants." *American Journal of Hospice and Palliative Medicine* 25, no. 3: 195-206. <http://ajh.sagepub.com/cgi/content/abstract/25/3/195>.
- Breedlove, Benjamin David. 2011. "This is My Story (Parts 1 & 2).
<http://www.youtube.com/watch?v=tmlTHfVaU9o>.
- Bronner, Simon. 2009. "Digitalizing and Virtualizing Folklore." In *Folklore and the Internet: Vernacular Expression in a Digital World*, ed. Trevor J. Blank, 21-66. Logan: Utah State University Press.

- Buccitelli, Anthony Bak. 2012. "Performance 2.0: Observations toward a Theory of the Digital Performance of Folklore." In *Folk Culture in the Digital Age: The Emergent Dynamics of Human Interaction*, ed. Trevor J. Blank, pp. 60-84. Logan: Utah State University Press.
- Burpo, Todd and Linda Vincent. 2010. *Heaven is for Real: A Little Boy's Astounding Story of His Trip to Heaven and Back*. New York: Thomas Nelson.
- Bush, Nancy Evans. 2012. *Dancing Past the Dark: Distressing Near-Death Experiences*. Cleveland, TN: Parson's Porch Books.
- Bynum, Chris. 2009. "Author Marilyn A. Mendoza visits New Orleans to sign 'We Do Not Die Alone': Jesus is Coming to Greet Me in a White Pickup Truck." http://blog.nola.com/chrisbynum/2009/01/deathbed_visions_comfort_the_d.html.
- Callanan, Maggie, and Patricia Kelley. 1997 [1992]. *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. New York: Bantam Books.
- Cole, Phyllis. 1992. "The Construction of Hospice and the Hospice Patient through Storytelling." *Folklore Forum* 25, no. 1: 29-40.
- Curtis, Leslee, 2012. "Deathbed Visions: Social Workers' Experiences, Perspectives, Therapeutic Responses, and Direction for Practice." *Master of Social Work Research Papers*. Paper 17. http://sophia.stkate.edu/msw_papers/17.
- Dégh, Linda. 2001. *Legend and Belief: Dialectics of a Folklore Genre*. Bloomington: Indiana University Press.
- Dégh, Linda and Andrew Vázsonyi. 1973. "Dialectics of the Legend." *Folklore Preprint Series* 6. Bloomington: Indiana University Folklore Institute.
- _____. 1974. "The Memorate and the Proto-Memorate." *Journal of American Folklore*. 87, no. 345: 225-39.
- Ellis, Bill. 2002. "Making a Big Apple Crumble: The Role of Humor in Constructing A Global Response to Disaster." *New Directions in Folklore* 6. <https://scholarworks.in.edu/dspace/handle/2022/6911>.
- Fenwick, Peter and Elizabeth Fenwick. 1997. *The Truth in the Light: An Investigation of over 300 Near-Death Experiences*. New York: Berkley Trade.
- Fine, Gary Alan. 1994. "Ten Lies of Ethnography: Moral Dilemmas of Field Research." *Journal of Contemporary Ethnography* 22, no. 3: 267-94. http://www.cts.cunji.cz/~konopas/liter/Fine_Ten%20Lies%20of%Ethnography.htm.

- Fischer, Michael M. J. 1986. "Ethnicity and the Post-Modern Arts of Memory." In *Writing Culture: the Poetics and Politics of Ethnography*, eds. James Clifford and George E. Marcus, 194-233. Berkeley: University of California Press.
- Foote, Monica. 2007. "Userpicks: Cyber Folk Art in the Early 21st Century." *Folklore Forum* 37, no. 1: 27-38.
- Frank, Arthur. 1997. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago, IL: University of Chicago Press.
- Frank, Russell. 2011. *Newslore: Contemporary Folklore on the Internet*. Jackson: University Press of Mississippi.
- Garcia, Angela Cora, Alecea I. Standlee, Jennifer Bechkoff, and Yan Cui. 2009. "Ethnographic Approaches to the Internet and Computer-Mediated Communication." *Journal of Contemporary Ethnography* 38, no. 1: 52-84.
<http://jce.sagepub.com/content/38/1/52>.
- Gelfand, Donald E., Richard Raspa, Sherylyn H. Briller, and Stephanie Myers Schim, eds. 2005. *End-of-Life Stories: Crossing Disciplinary Boundaries*. Death and Suicide Series. New York: Springer Publishing Company.
- Goldstein, Diane E. 2004. *Once Upon a Virus: AIDS Legends and Vernacular Risk Perception*. Logan: Utah State University Press.
- _____. 2007. "Scientific Rationalism and Supernatural Experience Narratives." In *Haunting Experiences: Ghosts in Contemporary Folklore*, eds. Diane E. Goldstein, Sylvia Ann Grider, and Jeannie Banks Thomas, 60-78. Logan: Utah State University Press.
- Grayson, Katharine. 2012. "Website Creates Community—and Cash." *Minneapolis/St. Paul Business Journal* (November 21). <http://www.bizjournals.com/twincities/print-edition/2012/11/23/he-built-a-site-then-a-community.html>.
- Greyson, Bruce, and Nancy Evans Bush. 1992. "Distressing Near-Death Experiences." *Psychiatry* 55: 95-110.
- Gupta, Akhil and James Ferguson. 1997. *Anthropological Locations: Boundaries and Grounds of a Field Science*. Berkeley: University of California Press.
- Hine, Christine. 2000. *Virtual Ethnography*. London: Sage.
- Holden, Janice Miner, Bruce Greyson, and Debbie James, eds. 2009. *The Handbook of Near-Death Experiences: Thirty Years of Investigation*. New York: Praeger.
- Howard, Robert Glenn. 2005. "Toward a Theory of the World Wide Web Vernacular: The Case for Pet Cloning." *Journal of Folklore Research* 42, no. 3: 323-60.

- _____. 2008a. "Electronic Hybridity: The Persistent Processes of the Vernacular Web." *Journal of American Folklore* 121, no. 480: 192-218.
- _____. 2008b. "The Vernacular Web of Participatory Media." *Critical Studies in Media Communication* 25, no. 5: 490-513.
- _____. 2009. "Crusading on the Vernacular Web: The Folk Beliefs and Practices of Online Spiritual Warfare." In *Folklore and the Internet: Vernacular Expression in a Digital World*, ed. Trevor J. Blank, 159-74. Logan: Utah State University Press.
- _____. 2011. *Digital Jesus: The Making of a New Christian Fundamentalist Community on the Internet*. New York: New York University Press.
- _____. 2012. "How Counterculture Helped Put the 'Vernacular' in Vernacular Webs." In *Folk Culture in the Digital Age: The Emergent Dynamics of Human Interaction*, ed. Trevor J. Blank, 25-45. Logan: Utah State University Press.
- _____. 2013. "Vernacular Authority: Critically Engaging 'Tradition'." In *Tradition in the Twenty-First Century: Locating the Role of the Past in the Present*, eds. Trevor J. Blank and Robert Glenn Howard, 72-99. Logan: Utah State University Press.
- Hufford, David J. 1982. *Terror that Comes in the Night: An Experience-Centered Study of Supernatural Assault Traditions*. Philadelphia: University of Pennsylvania Press.
- _____. 1995. "Beings Without Bodies: An Experience-Centered Theory of the Belief in Spirits." In *Out of the Ordinary: Folklore & the Supernatural*, ed. Barbara Walker, 11-45. Logan: Utah State University Press.
- Hunter, Kathryn Montgomery. 1991. *Doctors' Stories: The Narrative Structure of Medical Knowledge*. Princeton, NJ: Princeton University Press.
- Jones, Louis C. 1977 [1959]. *Things that Go Bump in the Night: Haunted Trails & Ghostly Tales*. New York: Hill and Wang.
- Kessler, David. 2011 [2010]. *Visions, Trips, and Crowded Rooms: Who and What You See Before You Die*. Carlsbad, CA: Hay House.
- Kinsella, Thomas. 2011. *Legend-Tripping Online: Supernatural Folklore and the Search for Ong's Hat*. Jackson: University Press of Mississippi.
- Kitta, Andrea. 2011. *Vaccinations and Public Concern in History: Legend, Rumor, and Risk Perception*. Studies in the History of Science, Technology and Medicine. New York: Routledge.
- Kübler-Ross, Elisabeth. 1997 [1969]. *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*. New York: Scribner.

- _____. 1999. *The Tunnel and the Light: Essential Insights on Living and Dying*. New York: Marlowe & Co.
- _____. 2000 [1971]. "What Is It Like to Be Dying?" *The American Journal of Nursing* 100, no. 10: 96.
- Labov, William, and Joshua Waletzky. 1967. "Narrative Analysis: Oral Versions of Personal Experience." In *Essays on the Verbal and Visual Arts*, ed. June Helm, 12-44. Proceedings of the 1966 Annual Meeting of the American Ethnological Society. Seattle: University of Washington Press.
- Langlois, Janet. 2005. "'Celebrating Arabs': Tracing Legend and Rumor Labyrinths in Post-9/11 Detroit." *Journal of American Folklore* 118, no. 468: 219-36.
- _____. 2008. "Confessions of a Legend Hunter in the USA." *Cahiers de Littérature Orale* 63-64 (Special issue: Pratiques d'enquêtes, eds. Brunhilde Biebuyck, Sandra Bornand and Cécile Leguy): 185-99.
- Madden, Mary. 2010. "Older Adults and Social Media." Pew Internet and American Life Project, <http://www.pewinternet.org/Reports/2010/Older-Adults-and-Social-Media.aspx>.
- Mattingly, Cheryl and Linda C. Garro, eds. 2000. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press.
- McCarl, Robert S. 1986. "Occupational Folklore." In *Folk Groups and Folklore Genres: An Introduction*, ed. Elliott Oring, 71-89. Logan: Utah State University Press.
- McClelland, Bruce. 2000. "Online Orality: The Internet, Folklore, and Culture in Russia." In *Culture and Technology in New Europe: Civic Discourse in Transformation in Post-Communist Nations*, ed. Laura B. Lengel, 179-91. Stamford, CT: Ablex.
- McNeill, Lynne S. "The End of the Internet: A Folk Response to the Provision of Infinite Choice." In *Folklore and the Internet: Vernacular Expression in a Digital World*, ed. Trevor J. Blank, 80-97. Logan: Utah State University Press.
- Mendoza, Marilyn A. 2008. *We Do Not Die Alone: "Jesus is Coming to Get Me in a White Pickup Truck"*. Dahlonega, GA: ICAN Publishing, Inc.
- Miller, Montana. 2012. "Face-to Face with the Digital Folk: The Ethics of Fieldwork on Facebook." In *Folk Culture in the Digital Age: The Emergent Dynamics of Human Interaction*, ed. Trevor J. Blank, 212-32. Logan: Utah State University Press.
- Moody, Raymond A. 2001 [1975]. *Life after Life: The Investigation of a Phenomenon—Survival of Bodily Death*. New York: HarperOne.

- Moody, Raymond A., and Paul Perry. 1993. *Reunions: Visionary Encounters with Departed Loved Ones*. New York: Villard Books.
- Nuland, Shervin B. 1995 [1993]. *How We Die: Reflections on Life's Final Chapter*. New York: Vintage Books.
- Osis, Karlis and Erlendur Haraldsson. 1997 [1977]. *At the Hour of Death*. 3rd ed. Norwalk, CT: Hastings House.
- Parker, Frances Shani. 2007. *Becoming Dead Right: A Hospice Volunteer in Urban Nursing Homes*. Ann Arbor, MI: Loving Healing Press.
- Parnia, Sam. 2014. *Erasing Death: The Science that is Rewriting the Boundaries Between Life and Death*. New York: HarperOne.
- Prensky, Marc. 2001. "Digital Natives, Digital Immigrants, Part II: Do They Really Think Differently?" *On the Horizon* 9, no. 6: 1-6.
- Rawlings, Maurice. 1993. *To Hell and Back*. Nashville, TN: Thomas Nelson.
- Rees, W. Dewi. 1971. "The Hallucinations of Widowhood." *British Medical Journal* 4, no. 5778: 37-41.
- Ring, Kenneth. 2006. *Lessons from the Light: What We Learn from the Near-Death Experience*. Portsmouth, NH: Moment Point Press.
- Roach, Mary. 2005. *Spook: Science Tackles the Afterlife*. New York: W.W. Norton.
- Rodriquez, Jason. 2009. "Attributions of Agency and the Construction of Moral Order: Dementia, Death, and Dignity in Nursing-Home Care." *Social Psychology Quarterly* 72, no. 2: 163-79. <http://spq.sagepub.com/content/72/2/165.abstract>.
- Sacks, Oliver. 2012. *Hallucinations*. New York: Alfred A. Knopf.
- Siebold, Cathy. 1992. *The Hospice Movement: Easing Death's Pains*. Social Movements Past and Present Series. New York: Twayne Publishers.
- Tangherlini, Timothy R. 1998. *Talking Trauma: Paramedics and Their Stories*. Jackson: University Press of Mississippi.
- Thompson, Stith. 1960. *Motif Index of Folk Literature: A Classification of Narrative Elements in Folktales, Ballads, Myths, Fables, Mediaeval Romances, Exempla, Fabliaux, Jest-Books and Local Legends*. Rev. & Enl ed. 6 volumes. Bloomington: Indiana University Press.

- Tucker, Elizabeth. 2009. "Guardians of the Living: Characterization of Missing Women on the Internet." In *Folklore and the Internet: Vernacular Expression in a Digital World*, ed. Trevor J. Blank, 67-79. Logan: Utah State University Press.
- Turkle, Sherry. 1995. *Life on the Screen: Identity in the Age of the Internet*. New York: Simon and Schuster.
- Wittel, Andreas. 2000. "Ethnography on the Move: From Field to Net to Internet." *FQS Forum: Qualitative Social Research/SozialForschung* 1, no. 1: 1-8.
<http://www.qualitative-research.net/index.php/fqs/article/view/1131/2517>.
- Zaleski, Carol. 1987. *Otherworld Journeys: Accounts of Near-Death Experience in Medieval and Modern Times*. New York: Oxford University Press.
- Zeitlin, Steve, and Ilana Harlow. 2001. *Giving a Voice to Sorrow: Personal Responses to Death and Mourning*. New York: Perigee Trade.

Langlois – “They All See Dead People...”

APPENDIX A

(Other Worlds IIA Research Informed Consent Form)

Research Informed Consent

Title of Study: “Other Worlds”: An Ethnographic Study of Personal Accounts of the Return of the Dead and Other Mystical Experiences in Health-Related Contexts
Part II A Hospital/Hospice Staff and Volunteers

You are being asked to be in a research study of accounts of mystical experiences in health-related contexts because you are either a hospital or hospice staff member or volunteer who may have observed such incidents concerning your patients and/or their relatives, friends and caregivers in end-of-life situations. Mystical experiences may include, but are not limited to, a sense of the presence of deceased persons or spiritual beings, premonitions of death, and dreams or visions.

The study is being conducted at Wayne State University, Detroit, MI, at [hospice name and location] and at other off-campus sites. Please read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Janet L. Langlois, Ph.D., English Department, and a Center to Advance Palliative-Care Excellence (CAPE) Associate, Wayne State University, Detroit, MI.

Study Purpose:

The purpose of the study is to document and analyze mystical narratives in health-related contexts such as hospices, hospitals and home settings. The study is related to other qualitative studies in the fields of medicine and humanities that evaluate the roles of storytelling in healing, illness, and end-of-life situations. Research results will be published in article and book form. The estimated number of study participants to be enrolled at Wayne State University and [participating hospice] is about 100 as well as about 200 throughout the U.S.

Study Procedures:

If you take part in the study, you will be asked to take a brief survey questionnaire and to have a follow-up interview with your permission. The questionnaire will take about 20 minutes, the follow-up interview about one hour. You will be asked about the mystical experience or experiences you noted without revealing your patients’ identities, how you interpret the event or events, your background information including how and why you have come to your present position in a hospice or hospital unit, and situations in which you have or have not spoken about your experience to others. You have the option of not answering some of the questions and remaining in the study. Your permission will be asked to audio-tape your follow-up interview, and the tape will be transcribed.

You have the option of completing the questionnaire only, or having the interview only.

Benefits:

The possible benefits to you for taking part in this study may include alerting you and other caregivers to these mystical experiences, or confirming your own observations of them, so that you can respond in medically-appropriate ways. Additionally, information from this study may benefit other people now or in the future. Research presentations and publications will be donated to your institution’s library.

Risks:

By taking part in this study, your risks are minimal, but may include recognition of job stress. There may also be risks involved in taking part in this study that are not known to researchers at this time.

Compensation:

You will not be paid for taking part in this study.

Confidentiality:

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Audio tapes will be kept in locked cabinets, and will be destroyed three years after the completion of the study. Information that identifies you personally will not be released without your written permission. However, the Human Investigation Committee (HIC) at Wayne State University or federal agencies with appropriate regulatory oversight may review your records.

Voluntary Participation/ Withdrawal:

Taking part in this study is voluntary. You may choose not to take part in this study, or if you decide to take part, you can change your mind later and withdraw from the study. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with Wayne State University or its affiliates or other services you are entitled to receive.

Questions:

If you have any questions now or in the future, or if you think that you need to report a research related injury, you may contact Janet L. Langlois or one of her research team members at the following phone number (313) 882-5657 or at ad5634@wayne.edu. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628.

Consent to Participate in a Research Study:

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study, you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read or had read to you this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

Signature of Participant/Legally Authorized Representative

Date

Printed Name of Participant/ Authorized Representative

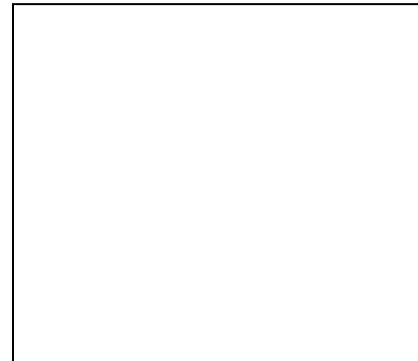
Time

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

Time



** Use when participant has had consent form read to them (i.e., illiterate, legally blind, translated into foreign language).

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APPENDIX B

Other Worlds IIA (OWIIA) Questionnaire for Hospital and Hospice Staff and Volunteers Form

Questionnaire for Hospice Staff & Volunteers (Part IIA), Page 1 of 5

1. Today's date (Month/day/year): _____

2. Your background:

Sex: _____

Age: _____

Education (Highest Level): _____

Ethnic group/s: _____

Religion: _____

3. Current job title/s (Check all that apply):

- Attending Physician
- Bereavement Coordinator/Manager
- Hospice Medical Director
- Hospice Doctor
- Hospice Nurse
- Nursing Assistant (CENA)
- Pastoral Counselor
- Social Worker
- Social Work Assistant
- Support Staff
- Volunteer (specific duties): _____
- Other, please note title: _____

4. How long have you worked at the present facility? _____

5. How long had you worked at another similar facility or position? _____

6. Please briefly describe why you entered hospice work?

7. About how many patients have you treated/attended during a terminal illness? _____

8. About how many patients have you witnessed in the active phase of dying or at the moment of death? _____

9. Did any patients seem to see or sense persons not present to other observers?

Yes

Estimated number of cases: _____

No

Skip to #12.

10. Were the persons present to the patients but not to other observers (check all that apply and specify who if possible):

- someone living? _____
- someone dead? _____
- a religious figure or mythological being? _____
- any combination of above? _____
- Unidentifiable?

11. Please briefly describe one typical case you observed of persons present to the patient but not to other observers:

12. Did any patients seem to experience being in surroundings other than their homes, hospice or hospital facility?

- Yes Estimated number of cases: _____
- No Skip to # 15.

13. Were the surroundings (check all that apply and specify where if possible):

- Familiar to patients? _____
- Earlier in time? _____
- "Other Worlds" in a religious sense? _____
- Any combination of the above? _____
- Other situations (specify)? _____
- Unidentified surroundings? _____

14. Please briefly describe one typical case you observed of patient's sense of being in other surroundings:

15. Have you had any patients who seemed to experience other mystical or unusual events at or before the time of their deaths (premonition of death, waiting for relatives or friends to come before dying, dreams, etc.)?

- Yes Estimated number of cases: _____
 No Skip to # 17.

16. Please briefly describe one typical case that you have observed:

17. Have you seen or heard that someone else (relative or friend of patient, staff member, etc.) seemed to experience something mystical or unusual around the time of, or after the death of, a patient (dreams, visions while awake, sense of the presence of deceased person, unusual occurrences, familiar smells, sounds, etc.)?

- Yes Estimated number of cases: _____
 No Skip to #19.

18. Please briefly describe one typical experience of a person not the patient:

19. Please briefly describe how you have interpreted or explained any of the experiences described above. What did you believe they meant to the patient, family, friends or caregivers?

20. Have you yourself experienced something mystical or unusual around the time of, at, or after the death of a patient, friend or relative?

- Yes
- No

Estimated number of incidents: _____
Please skip to #22

21. Please briefly describe your experience:

22. If you have spoken to someone about any of the experiences above, please briefly describe the situations and to whom you spoke:

23. In thinking over these questions, do you have any further comments you would like to make?

24. May the PI, or a research assistant for volunteers, contact you for a follow-up interview on topics above?

- Yes
- No

See below.

THANK YOU FOR YOUR PARTICIPATION.

If you have agreed to a follow-up interview, please leave a contact phone number, email address, or mailing address here:
