

# Storytelling and Social Activism in Health Organizing

Management Communication Quarterly  
2017, Vol. 31(2) 314–320  
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DOI: 10.1177/0893318916688090  
journals.sagepub.com/home/mcq



**Lynn M. Harter<sup>1</sup>, Stephanie M. Pangborn<sup>1</sup>,  
Sonia Ivancic<sup>1</sup>, and Margaret M. Quinlan<sup>1</sup>**

Our scholarship is inspired by a belief that how we communicate about health influences the management of health resources. In the United States, we commonly talk, act, and organize care as if bodies can and ought to be fixed. Cultural metanarratives (e.g., technology is progress) institutionalize patterns of care and normative expectations (e.g., the eradication of disease). The characters shift across settings, but the storylines and props generally remain the same: the restoration of health through high-tech medical intervention. The restitution narrative and its organizing practices, though, are impoverished when a cure is not possible or desired (Frank, 2013). The integration of creative programming in health and human service contexts invites participants to “move beyond the limiting tropes” of deviance (Alemán & Helfrich, 2010, p. 11), rendering visible experiences minimized by scientific and bureaucratic logics. In this essay, we reflect on our experiences producing *A Beautiful Remedy* (Harter & Shaw, 2014) and *Creative Abundance* (Harter, Shaw, & Quinlan, 2015), nationally syndicated Public Broadcasting Service (PBS) documentaries that profile arts-based organizations. Collectively, their efforts answer vulnerability in ways that lie beyond the traditional grasp of health and human services.

Artists draw on narrative resources in attending to and joining with those who suffer, and enlarge the scope of care to more fully acknowledge the subjective experiences of patients and families. The organizations featured in our work invite participants to tell stories through art, about art,

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<sup>1</sup>Ohio University, Athens, USA

**Corresponding Author:**

Lynn M. Harter, Ohio University, Schoonover Center 400, Athens, OH 45701, USA.  
Email: harter@ohio.edu

and/or while engaged in the art-making process (Harter, Quinlan, & Ruhl, 2013). Every tale carries social significance and the transgressive capacity to reveal what has been otherwise hidden or silenced. Our fieldwork focused on (a) what storytelling does for participants and (b) how it works to shift the logics of health care organizing. Across settings, we witnessed the role of counternarratives in fostering relational and organizational change. In turn, we relied on narrative-based interventions to challenge institutional practices that limit possibilities for individuals living in vulnerable bodies.

We approach scholarship as theoretically informed social activism. Our research has contributed to an aesthetic and narrative turn in theorizing about health organizing (e.g., Harter, 2009, 2013; Harter, Leeman, Norander, Young, & Rawlins, 2008; Harter, Patterson, & Gerbensky-Kerber, 2010; Harter & Rawlins, 2011; Harter, Scott, Novak, Leeman, & Morris, 2006; Pangborn, 2016; Quinlan, 2010; Quinlan & Harter, 2010). Meanwhile, documentary filmmaking has extended the reach of our work to the general public and shifted the nature of our relationships with community partners. Although numerous storytelling forms exist, cinematic images appear in theaters, on television screens, and in digital environments. We consider our filmmaking as contributing to social change insofar as it reveals the limits of traditional health care organizing and “actualizes contemplative spaces for envisioning other worlds” (Harter, 2013, p. 335).

## **An Aesthetic and Narrative Turn in Health Organizing and Theorizing**

The communication discipline has a rich history of narrative theory, and communication scholars have contributed to the narrative turn in health care (Sharf, Harter, Yamasaki, & Haidet, 2011). Even so, scholars have been criticized for their lack of attention to the poetic potential of storytelling. “The use of a narrative lens for exploring the ways in which human beings understand and operate within complex social environments has grown exponentially,” noted Andrews (2014); yet “most of this work has not dwelled upon the machinations of human imagination in the production and interpretation of narrative” (pp. 1-2). A case in point: Communication scholars generally gravitate toward spoken or written texts (for notable exceptions, see Quinlan, 2010; Willer, 2012). Sharf (2009) urged scholars “to be careful about over-privileging the verbal such that other important sensory contributions are not recognized and credited” (p. 136). Our projects illustrate the merits of an aesthetic approach to storytelling that includes but reaches beyond linguistic signifying practices. We bring into focus the role of the imagination in

narrative sensemaking, particularly as it informs organizing care for individuals living with chronic conditions and/or life-threatening illnesses.

Crafting and consuming stories require participants to exercise their imagination. Charon (2006) positioned the imagination as a “muscular mechanism” by which individuals enter another time, place, and series of events. “The boldness of the imagination,” argued Charon, “is the courage to relinquish one’s own coherent experience of the world for another’s unexplored, unplumbed, potentially volatile viewpoint” (p. 112). Narrators exercise their imagination when they piece together fragments of past experience to make sense of present conditions and envision otherwise. In turn, narratives invite audiences to grasp events befalling others. People’s lives are defined by what is both included and overlooked in the telling of stories, a process that is nonetheless socially conditioned. As noted by Andrews (2014), “imagination, like knowledge, does not come out of nothingness, but is a creative synthesis which emanates from a particular location” (p. 7).

Envisioning otherwise is a meaning-making process fraught with difficulty. The organizing of care and human services, for example, generally remain guided by deficit-driven models and a restitution narrative (Frank, 2013). Cultural scripts (e.g., problem-dominated viewpoint) inform patterns of care (e.g., diagnosis and fix the problem) and outcomes (e.g., normalization). As a result, people served are positioned, if even advertently, as bundles of pathologies to be corrected. The limits of restitution narratives are revealed when medicine cannot fix embodied experiences (e.g., chronic conditions), when treatment involves further damage to the body (e.g., kidney failure due to chemotherapy), and/or when a return to a previous state is not desirable (e.g., addiction).

*Creative Abundance* (Harter et al., 2015) and *A Beautiful Remedy* (Harter & Shaw, 2014) profile how creative programming can be transformative for individuals marked as “other” or whose lives have been changed by acute illness. *Creative Abundance* profiles the efforts of Patty Mitchell and Susan Dlouhy, activists who reenvision and restructure sheltered workshops, organizations that offer a range of vocational and nonvocational programs for individuals with developmental disabilities including facility-based employment. Despite efforts to “think ability first,” workshops typically are funded based on people’s limitations and often fall short of community integration. Mitchell and Dlouhy position workshops as spaces for creative activity and illustrate the power of art to foster human expression, develop individuals’ skills and talents, create vocational opportunities, and build community. *A Beautiful Remedy* offers viewers a glimpse into the Arts in Medicine (AIM) program at MD Anderson Cancer Center. AIM provides art programming to pediatric, adolescent, and young adult patients and their families. The making

and viewing of art helps participants transform their social realities, and enlarges the scope of traditional medical practices. Complete blood counts (CBCs), bone marrow aspirations, and lumbar punctures offer an important but limited view of illness. Artists featured in these documentaries draw on asset-based techniques in responding to another's hardship.

*Creative Abundance* (Harter et al., 2015) and *A Beautiful Remedy* (Harter & Shaw, 2014) profile organizations that differ in scope, size, and purpose; yet each realizes in practice what several philosophers have endorsed: Artful encounters can develop richer relational, organizational, and communal life (e.g., Dewey, 1934/1980). The experience of chronic disability and cancer emerges in part from living in bodies marked as "different." Health and human services are guided by logics and practices that seek to normalize embodied differences. Organizations responsible for acute and chronic care are guided by restitution narratives (Frank, 2013). Yet restitution narratives are partial and incomplete perspectives, and in some cases destructive (e.g., societal isolation). The organizations featured in *Creative Abundance* and *A Beautiful Remedy* flip this script by integrating aesthetic rationalities and practices into health and human services dominated by scientific, instrumental, and deficit-based logics. Participating artists acknowledge and appreciate difference rather than simply normalize or accommodate it, the latter of which remain deeply entrenched in deficit-driven models of organizing (Harter & Rawlins, 2011). Artful encounters, in their finest moments, can help participants find beauty in perceived imperfections and, in turn, transform imperfections into strength. In this counternarrative, hope is no longer tethered to a "cure," and resilience is not limited to a return to a previous state or normalized expectations.

## Theoretically Informed Social Activism

We become the stories we know. Just as cultures offer arsenals of stories by which to live, public intellectuals can enlarge emplotments that are culturally available. (Harter, Norander, & Quinlan, 2007, p. 112)

None of us envisioned ourselves as filmmakers 10 years ago. We followed our curiosities to graduate school and with a commitment to social justice. Narrative theory became central to our scholarly agenda—a meaningful way to understand the organization of health and human services. We write from different temporal trajectories in our academic careers. Lynn is full professor whose life path intersected with the other authors through the doctoral program at Ohio University. Maggie is an associate professor, Stephanie is an assistant professor, and Sonia is a graduate student. Each author served as

part of the production team of one or both of the documentaries, and envision storytelling and creative analytic work as essential to their scholarship.

A central feature of storytelling is its ability to deal simultaneously with continuity and disruption, the dropped stitch, the not always so. Narratives recount plans gone awry. Through emplotment, narrators organize characters and actions in time and imply movement toward an end state (Ricoeur, 1984). A fundamental part of the narrating process is the “and then,” the constructing of a sequence of elements. The consequential linking of events demonstrates the human capacity to be both anchored by history and transported into the future. Storytelling matters. It *does* things for people. These theoretical sensibilities inform our understanding of organizational life and offer us a range of forms that appeal to audiences outside of the academy.

Documentary storytelling allows us to offer counternarratives into circulation, making vulnerable “bodies audibly and visibly present” (Harter, 2013, p. 332) and enabling audiences to be affected by the creative energies of arts-based practices that “have a visceral impact on everything they touch” (McNiff, 2004, p. 17). *Creative Abundance* (Harter et al., 2015) and *A Beautiful Remedy* (Harter & Shaw, 2014) challenge taken-for-granted understandings of what counts as well-being, the personal and relational possibilities waiting to be pursued amid health challenges, and how we ought to organize health and human services.

Our documentaries seek to accomplish two things. First, we invite contemplators to enter settings populated by well-intentioned individuals stymied by fossilized practices and “narrative inheritance” (Goodall, 2008). We acknowledge that organizations are created by human beings and sustained by their complicity; we celebrate artfully pursued storytelling that disrupts limiting hegemonic scripts about what counts as caregiving. Second, we help audiences imagine new normals. Things can always be otherwise. We envision our documentary work as social activism, cultural and artistic practices that critically interrogate pressing social issues through audiovisual storytelling. We seek to privilege previously silenced voices, transcend traditional storylines, and spark dialogue about other possibilities. We also acknowledge the partial and indeterminate nature of our work. No story is ever final or complete, and we hope audiences enter with critical and empathic imagination to craft their own livable truths.

### **Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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### Author Biographies

**Lynn M. Harter** is a professor and co-director of the Barbara Gerald Institute for Storytelling and Social Impact at Ohio University.

**Stephanie M. Pangborn** is an assistant professor in the Department of Communication at Clemson University.

**Sonia Ivacic** is a doctoral student in the School of Communication Studies at Ohio University.

**Margaret M. Quinlan** is an associate professor in the Department of Communication Studies at UNC Charlotte.