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Rhetorical Curation of Patient Art: How Community Literacy Scholars Can Contribute to Healthcare Professions

Maria Novotny

Abstract:

In the era of a global pandemic, this article claims that community literacy scholars are well poised to support challenges currently facing healthcare providers. To demonstrate this, I offer one example drawing on my work with The ART of Infertility and explain how I repurposed patient art and stories to curate emotional literacy amongst healthcare professionals. I argue that “rhetorical curation” is an innovative method that can support public engagement around stigmatized or underrepresented health experiences. I end with an invitation for community literacy scholars to build upon their expertise and design innovative public projects that contribute to improvements in healthcare.

Keywords

rhetorical curation, emotional literacy, reflection, patient art, healthcare, infertility

The COVID-19 pandemic has evoked a pause and recalibration in our daily lives. Simultaneously, the pandemic has asked us, as community literacy scholars and practitioners, to reflect on our role as public intellectuals. In doing so, we have been asked to confront the question: *What can we, as community-engaged scholars, do to improve the health of our communities?* My response is: a lot and not just regarding the pandemic and public health. Right now, the entire country faces direct challenges in accessing not only reliable and accurate health information, critical to health literacy, but also broader challenges to having affordable healthcare. Given these threats, I find that community literacy scholars have an increasing obligation to work alongside healthcare communities that are encountering barriers to receiving care.

Such a claim, I realize, may seem rather obvious on its surface. For instance, the related sub-field rhetoric of health and medicine (RHM) has gained much scholarly interest and parallels some of community literacy’s aims. RHM scholars are studying a range of literacy practices in health and medicine, such as the use of social media during in vitro fertilization (Johnson et al.) to how health information is shared between patients, medical interpreters, and providers (Gonzales and Bloom-Pojar). In their 2019 introduction to the *Rhetoric of Health & Medicine*, J. Blake Scott and Lisa

Melonçon claim that rhetorical scholarship produced by RHM scholars has positively contributed to those practicing, communicating, and caring for others in health and medicine. As health and medical stakeholders begin to value the work of RHM, so too have scholars in rhetoric, composition, and communication who see potential for their research to extend beyond university walls and contribute to new locations, like that of health and medicine.

My point in overviewing the contributions of RHM in the context of this journal is that we, as scholars in rhetoric, composition, and community literacy, *also* offer much to health and medicine. Our disciplinary training in community literacies and public writing also has the potential to intervene in the inadequacies of health and medicine. While the work of RHM often offers specific methodological responses to rhetorical dilemmas occurring at health and medical sites, community literacy scholarship can expand the purview of health—to scenes and stakeholders beyond those working in the clinic or hospital. All communities, because they are created and sustained as relationships between and amongst bodies, are health communities. As such, community literacy scholars understand the need to listen and learn how specific communities are impacted by health and medicine.

Much of the reason for this is because of the methodological commitments we carry forward in our work. For instance, Dawn Opel and Donnie Sackey in their guest introduction theorize *reciprocity* as a guiding concept which informs: (1) “how we define and categorize oppression before we enter communities;” (2) “how we gain access to the lives of people outside of universities;” (3) “a commitment to community partners in the interpretation of data and in how we tell stories that are not our own;” and (4) “an emphasis on scholarly activism, or commitment to effectuating change” (1). Their special issue aids in defining community literacy work as scholarship that not only contributes to disciplinary knowledge but also contributes to community knowledge.

Reciprocity then is a critical concept informing community work in healthcare for two reasons. One, it demands that we position ourselves and our relationships with communities in our work. In this way, it asks that we build an ethical backbone to our work by demanding transparency and critical reflection. For instance, reciprocity is built into my work because of my embodied positionality as an infertile woman. By being infertile and making that visible to all the communities I am a member of, I am embodying my own commitments to this community. When working with marginalized health communities, positionality is vital in building not just ethos but trust. Such is especially true considering how BIPOC communities have been unethically experimented on (i.e., Henrietta Lacks, the Tuskegee experiment, etc.) under the guise of advancing health research. In other words, reciprocity demands that our work cares for the very communities that make our work possible. Two, reciprocity invites a critical process to ensure that the outcomes of our work are not just shared with our communities (i.e., sharing our research article with the community), but have value and can be engaged by the very stakeholders our communities see as needing our research (i.e., developing a public engagement event for the community to be featured). In this way, reciprocity reshapes the outcomes of

our work by repositioning where and for whom our work has value: no longer solely within a disciplinary realm but demanding innovation in reexamining how our work engages publics.

By situating reciprocity as a core concept guiding my infertility scholarship, I have found myself asking: *How does my work improve the day-to-day lives of the fertility patient?* To answer this question, I share with readers how I have repurposed much of my patient narrative research “data” into an exhibit educating the public and healthcare professionals about the everyday challenges of an infertility diagnosis. In this way, I see reciprocity as an undercurrent guiding the development of this project and suggesting reciprocity as a useful concept to inform future community literacy scholarship in health and medicine.

In what follows, this article articulates the need for emotional literacy in fertility healthcare and, more broadly, how community literacy scholars can incorporate literacy work in the healthcare professions. To do this, I share how I designed a patient art exhibit using rhetorical curation to facilitate moments fostering attendees’ emotional literacies. I conclude with broader discussions about the role of the community-engaged scholar, the use of curation as a tool, and how emotional literacies impact experiences of health.

The Fertility Industry, Communicative Breakdowns, and the Need for Emotional Literacy

The fertility industry is booming with more people reportedly building their families using assisted reproductive technology (ART). On average, in the U.S. 1 in 8 couples are diagnosed with infertility, with 7.4 million women reporting they have used some form of assisted reproductive technology to build their family (“Fast Facts”). In fact, the Centers for Disease Control and Prevention (CDC) reports that about four million births per year in the U.S. are the result of in vitro fertilization (IVF) (“IVF By the Numbers”). Despite this large number of births, the American Society of Reproductive Medicine (ASRM) cites that on average it takes about five to six rounds of IVF before a patient becomes and maintains their pregnancy, resulting in a “take home baby.” These statistics, coupled with the reality that the out-of-pocket costs for one round of IVF on average cost \$12,000, perpetuate a real sense of patient anxiety and stress when undergoing treatment (Cousineau and Domar).

As such, when the patient comes to the fertility clinic, fertility healthcare providers often meet with anxious, stressed, perhaps even depressed patients hoping that ART will help them build their families. A 2018 study examining the communicative exchanges between the fertility patients and fertility providers, conducted by Robert Klitzman, found significant barriers to adequately addressing patients’ needs. One reason for these communicative breakdowns relates to the emotional extremes experienced by both the patient and the provider.

Klitzman’s study found significant communicative differences in how patients and providers emotionally responded to fertility treatments. While infertility patients reported feeling extremely anxious while talking with their fertility doctor, nurse, or

receptionist about a fertility treatment to even the statistics of them being able to carry a pregnancy term, Klitzman reported that providers in these moments desired to maintain a sense of medical objectivity when addressing patients' concerns. Talking with fertility providers about their communicative decisions, Klitzman found that these providers relied on communicating medical facts, as they reportedly felt remarkably underprepared to address the emotional complexities of patients. As a result of these communicative tensions, many infertility patients reported feeling angry and frustrated about the lack of emotional care they received while providers felt underprepared to offer emotional support in order to resolve the patients' anxiety.

One solution to resolve these emotional tensions, proposed by the study, centers around increasing the provider and their staff's emotional literacy by providing training events. Klitzman writes that "providers are insufficiently sensitive to these [emotional needs], reflecting in part lack of training and competing perspectives and promises" (6). Fertility clinics could improve patient care by offering more opportunities to develop not just clinical skills but emotional skills as well. Healthcare professional development events centered on emotional intelligence may improve the emotional literacies of fertility providers and staff and, thereby, improve the fertility patients' experience of care. An example of an emotionally literate curriculum includes reflective learning experiences and opportunities for working creatively with the arts and humanities (Freshwater and Stickley). In what follows, I recount how I designed an emotionally literate curriculum for a pharmaceutical company using rhetorical curation as a method. Doing so, I illustrate how disciplinary training in rhetoric and composition, broadly, and how methodological commitments guided by reciprocity can offer tools for community literacy scholars to contribute to the healthcare professions.

Applying Rhetorical Curation to a Professional Development Event

In 2017, a large, U.S.-based pharmaceutical company, manufacturing fertility drugs and products, invited The ART of Infertility to curate a 1-day pop-up patient art exhibit and educational talk during National Infertility Awareness Week. The objective of the event was to emphasize patient perspectives when undergoing fertility treatment. The rationale behind this objective was two-fold. First, those working at the pharmaceutical company often have limited knowledge of the complexities of an infertility diagnosis. For instance, while employees may understand or identify as supporting the infertile patient by developing effective treatments and products for the fertility doctor, they may have difficulty understanding the embodied experiences a patient undergoes when using the treatment or product. Second, some employed at the pharmaceutical company are tasked with developing effective marketing and branding of the treatment and drug. This task relies upon an informed understanding of the user of the drug or product. Yet, those working in the marketing department may have little knowledge of the lived experiences of the fertility patient. By inviting The ART of Infertility to curate an exhibit of patient art, the pharmaceutical company hoped that the exhibit would remind employees of the complex, embodied, and of-

ten rollercoaster of emotions that fertility patients encounter. To meet these aims, The ART of Infertility drew from the organization's archives of patient art and narratives to create an event that modeled emotional literacy curriculums by using art, story, and reflection to build emotional awareness around infertility.

As The ART of Infertility began to discuss the design of the event, we decided to engage in the practice of what we call "rhetorical curation." Rhetorical curation is a practice that applies the rhetorical situation, i.e. the texts, audience, purpose, and setting, to inform the creation of the exhibit. Such a practice is locally responsive to the specific settings, audiences, and purpose of the exhibit. We saw rhetorical curation as helpful to informing the design of this project as it allowed us to account for both the complexities and nuances when representing "infertility" as well as useful to accounting for the variety of perspectives, knowledges, and experiences viewers at this employee event would have about the topic.

The Texts

The primary texts for the event would consist of patient art and stories selected from The ART of Infertility's permanent collection. Artwork was selected based upon a variety of mediums to visually engage the viewer while also considering the corresponding story with the art. Meaning, each piece of patient art is displayed with a brief artist narrative that provides context around the significance of the piece of art in relationship to their infertility experience. For instance, while the artist may choose to depict their experience via a sunflower, the narrative may explain the symbolism behind the sunflower and the artist's infertility. Given the location of the pop-up exhibit and use of tables to display art and stories, around forty pieces of art and their corresponding narratives were displayed.

Secondary texts included infertility statistics and recordings of patient oral histories, which would be presented during the educational talk. These texts were selected in order to provide context on the number of people facing an infertility diagnosis, the challenges infertility patients face, and hearing patients recount these challenges in their own words.

The Audience

As an event hosted at a pharmaceutical company, the audience included a range of employees including pharmaceutical representatives, product managers, engineers, product designers, and marketing/sales teams. Given the range of employees, it was expected that there would be various levels of comfort in understanding an infertility diagnosis.

The Setting

The event was hosted on-site at the pharmaceutical company's U.S headquarters. The talk and the exhibit space would occur in separate rooms, with the talk allowing for a

more formal presentation and the exhibit space hosted in a frequented hallway to encourage employees to peruse the pieces between meetings and appointments.

The Purpose

Broadly, the purpose of this event was to offer patient-centered education in coordination with National Infertility Awareness Week. As a company that develops, manufactures, and markets several fertility drugs and products, the purpose of the event was to foster employees' emotional literacies around infertility. The idea resonated with the pharmaceutical company's mission to offer compassionate care.

Focusing on these four areas allowed us to construct a professional development embracing elements of emotional intelligence and inviting employees to emotionally engage with infertility. In what follows, I share what occurred the day of the event.

The Pharmaceutical Event

The day of the event began by setting up the exhibit. By rhetorically curating the event and selecting the pieces of art to be displayed prior to the event, we were able to quickly install a 40-piece pop-up exhibit. With the exhibit set up, we moved to the educational talk portion of the event. The structure of the talk incorporated statistics about infertility, our personal history as prior fertility patients, slides containing patient artwork and their art label, patient portraits and their fertility narratives, and even poetry recited by former patients. To be clear, the patient stories that were represented were not all success stories. Meaning, not all the stories shared demonstrated a sense of empowerment over their fertility after using one of the pharmaceutical drugs or products. This was intentional, as we wanted to emphasize statistics that contradict public assumptions that assisted reproductive technologies are often successful. A question and answer session followed the talk.

Employees were then invited to stop by the pop-up exhibit throughout the day to view patient artwork and read narrative labels that described the meaning behind such art. To encourage viewing, the company hired a barista to set up near the exhibit and offer coffee and snacks free of charge to employees. Two examples of artwork shown appear below in images 1 and 2.



Image 1.



Image 2.

One critical component of the event was to include the opportunity for employees to reflect and share their insights with each other. Wanting to gather data and measure how employees were developing emotional literacies about infertility, we set up a table alongside the exhibit with a series of notecards with the phrases “Infertility is...” and “Life without my children would be...” Instructions were placed on the table and invited employees to fill out a card and then post on a corkboard as part of an interactive component of the event. While not mandatory, the intention was to encourage employees to engage in reflective learning offered by the exhibit. This strategic use of reflection follows what Sara Horton-Deutsch and Gwen Sherwood have found as essential to developing emotionally-competent healthcare workers: reflection as key to fostering emotional intelligence and thereby enhancing emotional literacy. As such, the reflective cards were designed to help us measure the emotional impact of the exhibit. Image 3 below offers a snapshot of the feedback.



Image 3.

Using Reflection to Assess Emotional Literacy

Following the event, I gathered the reflective cards created and posted during the exhibit and later transcribed the reflective feedback provided by employees at the event. In total, there were seven responses posted under “Infertility is...” with one additional response that crossed out “Living without my child would be” to read “Living without children...” Because this response appeared purposefully hacked and placed under the “Infertility is...” section, I counted this response there. As such, I tallied a total of eight responses for the prompt “Infertility is... write on the cards telling us what infertility is to you.”

A total of nine responses were received under the prompt “Living without my children would be...” The card was further explained with a prompt “Those diagnosed with infertility are faced with the possibility that they may never have children. If you have a child, or children, what would life without them be like for you? Give it some thought for a better perspective on what receiving an infertility diagnosis might feel like. Then, write it on the cards to let us know.”

After transcribing each response, I used discourse analysis (Gee) to analyze each response, coding each by applying Daniel Goleman’s model for emotional intelligence domains. Goleman’s emotional intelligence framework was developed in the mid 1990s using the Emotional Intelligence Competency Inventory. From that, Goleman initially found five domains of emotional intelligence, which were then collapsed into four. These four domains include: (1) self-awareness, (2) self-management, (3) social awareness, and (4) social/relationship management. Within each domain are multiple competencies. Table 1, attributed from Barbara Kooker, Jan Shoultz, and Estelle Codier’s emotional intelligence nursing study, illustrates the four domains and competencies.

Table 1.

Domain	Self-Awareness	Social Awareness	Self-Management	Relationship Management
Competencies	Emotional self-awareness Accurate Self-assessment Self-confidence	Empathy Service orientation Organizational Awareness	Emotional self-control Trustworthiness Conscientiousness Adaptability Achievement orientation Optimism	Developing others Inspirational leadership Influence Teamwork Change catalyst Conflict management

In the example below, I walk readers through how I coded each reflective response using Goleman’s model by first reading a transcribed response and then identifying any visible competencies within each response. Take the card below in image 4:

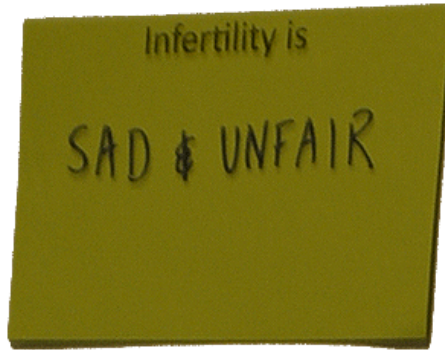


Image 4.

This card was placed under the prompt “Infertility is...” I transcribed it to read: “Infertility is... sad & unfair.” Using discourse analysis, I coded this card as falling under three of Goleman’s domains: (1) self-awareness, as it alludes to a personal emotion with the word “sad,” (2) social awareness, as it alludes to an orientation beyond oneself with the word “unfair,” and (3) relationship management as it indicates a need to enact change. This process was then replicated for the seventeen other reflective postings found on image 3.

The appearance of the four domains seems to suggest that attendees at this event were able to develop some additional emotional awareness and literacy about their relationship to infertility. To be clear, we did not assess attendees’ emotional literacy prior to the event. In hindsight, we would have liked to incorporate an activity at the beginning of the event to capture the emotional literacies of each attendee so to assess how emotional literacy was further cultivated. Nonetheless, we do believe that the willingness to share a reflection after viewing the exhibit and attending the talk demonstrates how emotionally moved individuals were. No incentive was offered to compose emotional reflections by the pharmaceutical company and thus, we believe, signals a heightened sense of emotional literacy.

Emotional literacy is defined by Claude Steiner as the ability “to handle emotions in a way that improves your personal power and the quality of your life and—equally important—the quality of life of the people around you” (1). When emotional literacy is practiced, outcomes include (1) the improvement of relationships, (2) increasing cooperation, and (3) facilitating and addressing community needs (Steiner). While all three outcomes can positively benefit the individual person, the third outcome underscores the potential ripple effects and greater impact such programs and events fostering emotional literacy may have on communities and not just individuals.

By recounting how reflection was used to capture the emotional learning occurring at this event, I find that emotional literacy is particularly important not just in fertility care but in other healthcare professions as well. All too often there is an implicit understanding that valuable humanities-based healthcare work needs to happen with the very providers who will be working with patients. Yet, this case study invites us to expand that purview and to consider the range of healthcare professions

that could also benefit from our work, beyond doctors and nurses. Despite the fact that many pharmaceutical company employees do not work directly with fertility patients, many are in positions where they make decisions about how fertility patients experience treatment. For instance, while pharmaceutical employees may have less of a direct relationship with patients, their work, the design of the product, and the communication about the product has a direct impact on how patients embody their infertility. In this way, this example illustrates how community literacy scholars can critically imagine (Royster and Kirsch) new scenes and stakeholders their scholarship can reach. In the context of this article, community literacy can serve as a bridge to addressing needs in health and medicine.

A Call to Incorporate Community Literacy Work in the Health Professions

My intention in writing this article is to invite community literacy scholars to reimagine the product/s and purpose of our scholarship. Other community literacy scholars, and this journal in particular, have contributed to connecting writing and literacy to non-academic spaces including prisons (Barrett et al.; Cavallaro; Jacobi), disability advocacy centers (Konrad), and after-school health literacy programs (Del Hierro et al.). This article, however, calls upon community literacy scholars to consider their work in relationship to health and medicine. As scholars with bodies and connected to communities of bodies, the opportunities and breadth of how we may apply our disciplinary knowledge is vast. Furthermore, the daily managing of COVID-19 in our lives creates a particular exigence to apply our work to healthcare communities.

Additionally, many readers of this journal are working with community projects that result in the creation of some deliverable—whether that is creative writing, art, blogs, or performances. As writing and literacy scholars, we understand the value and insights those deliverables offer about those communities. For instance, visual artist and Conference on Community Writing Keynote Michelle Angele Ortiz explains that the public circulation of art through public art exhibits can act as “platforms for social change” (25). Ortiz’s work pushes the community-engaged scholar to consider how the deliverables our communities produce, when shared with others, can be “a way to record, reclaim, and elevate these stories that connect us to our humanity” (37).

Repurposing our scholarship into more visible public arenas, though, requires a particular type of care to ensure that the very communities we seek to empower are not further exploited when we move their community work into public spaces. To help ensure that care is core to the practices moving us towards more public scholarship, Ortiz offers a series of questions to help guide community-engaged scholars seeking to repurpose and share community work with others. She asks (1) “How do I begin to shift power structures?” (2) “How do I utilize my privilege, skills, and resources as a way of providing opportunities to others?” (3) “How can I support others to have courage to share their stories, especially in spaces where they are not represented?” (37). These questions can be addressed by embracing the concept of reciprocity in our work.

And by returning to reciprocity, we must reimagine what we as a discipline come to value with our work. No longer can we remain siloed in our approach to community work: publishing about a community rather than co-creating public research-informed experience with a community. There is a difference in these approaches. My point in raising these two orientations to community work is to be more cognizant of the impact and outcomes of our work. If we truly want to improve the lives of bodies in need of care, if we see community literacy scholarship as valuable to the health professions, then we need to rethink the products our scholarship produces. In short, we—community literacy scholars—need to begin discussing how we effectively and ethically do public work, especially as we identify more non-academic spaces that could benefit from our expertise. Rhetorical curation is just one out of many methods we can draw on to improve care in communities. Believing this, I end this article with an invitation for you: *How may you practice care?*

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