

Negotiating the Ethics of Representation in RHM Research

Melissa Carrion

Drawing from my experience conducting an interview study on vaccine hesitancy, this essay explores the ethical negotiations RHM researchers face when recruiting participants from online communities, and especially communities that are stigmatized or otherwise distrustful of researchers. I discuss the specific challenges I faced during this process, and offer four suggestions for researchers engaged in this work. These include the valuable role of reflexive journaling, the need for participant input in the distribution of recruitment messages, the importance of accounting for the dynamic nature of online communication, and the ways that participant communication online may shape off-line interactions. This essay can offer guidance to RHM scholars facing similar situations, and contribute to the broader conversation about practice-level ethical concerns in RHM research involving online communities

KEYWORDS: online recruitment, interviews, reflexive journaling, feminist research ethics, vaccine hesitancy, qualitative research, recruiting, ethics, feminist

Prologue

I waited with bated breath. After weeks of waiting for IRB and administrative approvals, the recruitment message would not only be posted but would be done so under the auspices of the babycenter team. My perfectly crafted recruitment. There it was.

Ethics of Representation in RHM Research

"Hello! My name is Melissa Carrion, and I am a doctoral candidate in the School of Communication at Purdue University, as well as the mother of a three-year-old son."

Perfect. Surely this established legitimacy. I am a researcher, but more than that, I know what it is to wipe someone else's butt after they poop. We are sisters.

"I am currently conducting research for my dissertation on why mothers choose to forego vaccinations for their children, and specifically the concerns and other factors that influence this decision. I am interested in interviewing mothers who have given birth or adopted a child within the past two years and who have either foregone or plan to forego one or more vaccination. These interviews would take place over the phone (scheduled at their convenience) and would last approximately one hour. Participants would be compensated with a \$20 gift certificate to amazon.com, which would be emailed directly to an address you provide."

Yes. I had struggled over whether to use the word "refuse" or "forego"—I opted for what I perceived to be the gentler language. This seemed clear, unbiased, and convenient. And, there was money in it—what wasn't to like?

"If you are interested in participating or learning more, please email me at [email address]. I am happy to provide a list of interview questions in advance. This research study is approved by the Institutional Review Board of [name] University (IRB Protocol #1305013623), under the advisement of [name]. Thanks for your time!"

There was an institutional email address and IRB approval from a respected research university. The offer to provide questions in advance would surely quell further doubts. I topped this off with an expression of gratitude and an exclamation mark. The less formal "thanks" conveyed what I hoped was a friendly and non-stuffy demeanor. I would be fun to talk with.

There it was. I read it in delight. It was perfect. Exhale. Then it wasn't. Sharp inhale.

"*Sounds fishy*" wrote magnolia5, within seconds. For this, she received six virtual hugs from the community. "*I wouldn't touch this with a ten foot pole,*" added mrssunshine, whose online signature encouraged us to purchase

Carrion

a dreamcatcher from her Etsy shop. This only seconds after magnolia5. Her comment got seven hugs.

There my post remained, sans hugs. I hugged myself. It continued.

“Can’t find a thing on that “protocol #”. You’d think it would be searchable on line.” Hmmm, I thought. Maybe this isn’t about me at all. The Internet is filled with scams, this could be about anything. Swede050’s point garnered a single hug.

“Hell no and i wouldn’t give out my address even with the promise of a gift card lol! Nor would i want them to have my phone number. something sounds off. like they honestly care why we don’t vaccinate . . .” Samsmommy, and her four hugs, reminded me that this was indeed about me.

I was panicking. My husband walked in and I quickly explained the situation. Something needed to be done and fast. I hadn’t considered an online rebellion, a swift tide of community opinion that could shut me down as surely as an administrator denial. I typed out a message, trying to empathize with the suspicion but also demonstrate my legitimacy. By the time I was ready to post it, less than ten frantic minutes and one quick spousal copyedit later, others had come tentatively to my defense.

KerryM, whose virtual signature identified her as “Catholic and Crunchy,” wrote, *“I went to [university name]! I looked her up as a doctoral candidate on [university] website and she is who she says she is. Her research isn’t listed but sometimes only professors are. When I did research at [university] it was common to give nonstudent participants \$20 (amazon wasn’t around). I would safely say it is legit.”* She was backed up with five virtual hugs and comments from Kellybelly and sahm45 who agreed that it sounded “legit.”

Phew. Not out of the woods, though. Kellybelly continued, *“I think they care why we choose not to get some/all vaccines because they want to figure out how to convince us to change our minds.”*

Several things about kellybelly’s statement were revelatory for me. Yes, I was an advocate of vaccines, and when I thought about where this research would end up in terms of journals, practitioners, etc., it was within the context of promoting public vaccination. But at the same time, I was also a little bit scared of vaccines in ways that I tried to tell myself were completely irrational. Indeed, the existence of so many phenomena I saw in the literature about vaccine skepticism—from omission bias to the influence of narrative—I could testify to personally. In this sense, what I really wanted was to be convinced that I had been right all along with the added bonus of insights into how to best convince others of my rightness. (My husband will

—1
—0

Ethics of Representation in RHM Research

testify that this is much the way I approach marriage.) Kellybelly had figured me out quickly, and this worried me. Inhale.

But her use of the word “us” was the real biting epiphany. It was like a gestalt shift where the old crone becomes the young woman but with the added sting that comes with realizing you should have seen her all along. I wasn’t recruiting individual participants. This was a community. These people knew each other; they talked. If I blew it with one of them, I blew it with all of them. And there was Kellybelly’s insight, about ME, out there in the public sphere. Indeed, 4soul (whose signature identified her as “SAHM, doula, vegan, crunchy, attachment parenting, extended rearfacing, cloth diapering, 2 year old”) quickly asserted, “*I have a vote for who should represent us!*” This was an “us”, a “we.” I submitted my comment.

Hi,

Thanks so much for your posts. I understand that this might appear suspicious, and I also appreciate and understand your caution in responding to a stranger’s request for information. Although the Institutional Review Board protocol # is (unfortunately) not searchable online, if you have questions about research participation or would like to verify the study you can contact the [university] IRB directly at [email] or [phone #]. You can also find both me and [name] (my advisor) through [university program website], and you’ll find this study included among those funded by research development grants from the Organization for Research on Women and Communication <http://www.orwac.org/grant-recipients.html>. I hope that you’ll contact me by email with any further questions (or you can post them here). Thanks again!

Again, I worked to convey a friendly tone while I simultaneously legitimated and responded to their concerns. Those who followed the link to the Organization for Research on Women and Communication would find a listing of research projects clearly committed to social justice. Normally, I wouldn’t mention an advisor, but I felt doing so would make me appear less threatening. I waited again. My message was greeted with five hugs. Exhale.

Introduction

This excerpt was taken from the reflexive, narrative journal I kept while carrying out my dissertation research, a mixed-methods (rhetorical and

qualitative), interview-based study of the arguments underscoring maternal vaccine refusal. I begin with it because it illustrates the issue I hope to explore in this brief essay: namely, the ethical challenges associated with recruiting participants from online communities, and especially communities that are stigmatized or otherwise distrustful of researchers. This is an issue that researchers grapple with in a variety of disciplines, but is particularly relevant for RHM scholars wishing to include participant voices in the study of controversial health/medical ideas and practices.

To this end, I first provide an overview of the research project, its origins, and the questions I sought to answer. I describe the feminist ethical framework that shaped my approach to study design and my relationship with participants. Finally, I return to the excerpt from my narrative journal to highlight and reflect on three specific and unanticipated challenges I faced during this process, and which represent ethical considerations that are unique to online recruitment for offline research. I am hopeful that this essay can offer guidance to RHM scholars facing similar situations, and contribute to the broader conversation about practice-level ethical concerns in RHM research involving online communities (see De Hertogh, 2018; Opel, 2018).

Background and Research Questions: Mothers and Vaccines

Public health efforts to control many diseases rely on the herd immunity achieved through widespread vaccination. Accordingly, parental vaccine hesitancy and refusal present a major challenge, and researchers have worked hard to identify the factors that influence attitudes toward vaccines, ranging from concerns related to safety and efficacy (see Navin, Wasserman, Ahmad, & Bies, 2019) to ideological arguments about the role of government (see Bednarczyk, Tate, Opel, & Omer, 2017). Rhetorical approaches also have proven valuable in this endeavor, helping to identify the common arguments used in vaccine critical communities (Lawrence, 2020), exploring the ways that scientific communication practices can perpetuate vaccine controversy (Kolodziejcki, 2014), and investigating the way publics make sense of vaccine risks and benefits in a local context (Lawrence, Hausman, & Dannenberg, 2014).

My own initial interest in the subject was personal; the figurative birth of this project was the literal birth of my son following my first year in a

—1
—0

Ethics of Representation in RHM Research

Ph.D. program. As a researcher by training (and a worrier by disposition), I read all that I could about pregnancy, birth, and children's health, and was eager to talk and hear about others' experiences. This included discussion of vaccines. On a "rational" level, I was very much an advocate. We chose to have our son vaccinated according to the CDC's recommended schedule. At the same time, though, I was not immune to doubt, and was even sympathetic to some arguments I heard. In particular, I couldn't escape the feeling that decisions about vaccination were somehow a touchstone for broader and legitimate concerns—a blank screen onto which I could see projected debates about environmental risk and regulation, the pressures of motherhood, critical theories of knowledge and science, and a legacy of feminist rhetorics and epistemology. In short, it provided fecund ground for exploration, allowing me to draw from both my own experience as a new mother and my areas of academic focus: health communication, women's studies, and rhetoric. My ultimate research questions were refined through preliminary research, and reflect, respectively, these three disciplinary audiences:

RQ1: What reasons/arguments do participants provide for refusing vaccines for their child(ren)?

RQ2: How do participants discursively construct motherhood and the "good mother" in the context of vaccination?

RQ3: How do mothers' explanations for vaccine refusal challenge the boundaries between personal and technical argument?

A Feminist Ethical Framework for Study Design

These research questions called for a purposive sampling of non-vaccinating mothers, and I chose semi-structured interviews for their ability to capture participants' "rhetorical construction of their experience" (Lindlof & Taylor, 2002, p. 173). I interviewed 50 participants, a target I had set with the hope of reaching data saturation and ideally approaching a maximum variation sample in terms of participant demographics. (One committee member also strongly suggested to me that this number would make the research more publishable for health communication and public health audiences). Online parenting communities, which had been my own first exposure to

vaccine critical discourse, offered access to the exact participants I sought. It also seemed likely that participants who had already chosen to engage around this topic online would be willing to do so offline.

Other choices I made with regard to study design were guided by a feminist ethical framework attentive to transparency, balancing the research power dynamic, acknowledging researcher positionality, and considering participant insights as a valuable form of situated knowledge (Harding, 2004; Hesse-Biber & Yaiser, 2004; Kirsch, 1999). These choices reflected my feminist commitment on methodological and ideological levels, but also on an epistemological level. That is, the project took for granted the existence and acceptance of different ways of knowing, and that recognition necessarily required humility as a researcher and respect and gratitude for those willing to share their experiences. Accordingly, these tenets guided the research process from data collection to publication, including the decisions to provide interview questions in advance, to compensate participants for their time, and to ensure that my resulting publications represented participant voices with empathy. In the remainder of this essay, however, I focus in particular on how these tenets helped me to negotiate the unique challenges I faced during the recruitment process—specifically, the challenges of establishing trust and maintaining transparency in a real-time, ongoing, collective interaction.

Ethical Challenges: Online Recruitment for Offline Research

As my journal entry indicates, I had faced early challenges in gaining access to my chosen communities. I was purposeful in not orienting my research around the community itself, but rather using the community as a way of reaching a geographically diverse sample of individuals. Nevertheless, in response to ethical concerns about the blurry public/private distinction posed by online communities (Gelinas et al., 2017; McKee & Porter, 2009), I limited my recruitment efforts to groups that were classified as “public.” This meant that all posts and discussion were accessible to anyone and discoverable via search engines (in contrast to “private” groups, which required moderator approval to join, view, or participate in any discussions). I also requested access approval at multiple levels, beginning with the general website administrators (i.e., individuals employed by the website for oversight and technical support) and then moving to explicit approval from the

—1
—0

Ethics of Representation in RHM Research

specific forum moderators (i.e., volunteer members who created and moderated specific discussion spaces). Again, this decision was about respecting the space as a community into which I was invited, rather than one I had somehow infiltrated. In fact, the first site for which I had secured administrator approval denied me access at the moderator level after the group talked it over and was not comfortable with someone coming in for research purposes, even for recruitment.

Administrators from the site from which I ultimately recruited, however, responded to my “first-level” email by immediately posting the recruitment message themselves (I had included it for reference in my request) directly to the forum I had identified. While the administrators were not directly involved in the forum itself, I assumed their willingness to post the message would be seen as a sign of my credibility. Having waited several weeks for a response, this seemed reasonable and even desirable. Moreover, although I was well aware of the affordances of online communities to foster two-way communication, I had imagined that—in using the community only for recruitment—the forum was more like a digital bulletin board onto which someone was affixing a flier. In hindsight, however, the administrator’s posting of the recruitment message was an unanticipated challenge that worked against the very ethical principle that had guided my initial strategy. That is, by denying participants the choice of my digital presence, I was immediately viewed as an outsider with suspect motives. I missed the opportunity to communicate directly with a moderator who could have felt agency in the decision and vouched for me.

This augmented the second challenge I faced in this process. Again, in imagining my recruitment message as a flier on a static bulletin board, I neglected to consider the possibility of the immediate feedback and questioning that emerged via the discussion forum. I had spent significant time considering the language of the recruitment message, and felt confident (as the journal entry indicates) in my ability to foster consubstantiality based on my position as a mother. However, I had also imagined this process of developing relationships with participants as a private and individualized one. I was entirely unprepared to address this publicly and collectively, and yet realized quickly that my ability to recruit participants likely hinged more on this spontaneous exigency than the procedural barriers for which I had worked so consciously to account. The specific nature of the concerns raised by participants—about my identity, legitimacy, and motives—also put me in the immediate situation of needing to balance transparency about my

Carrion

research goals with the possibility of alienating potential participants. Although my initial response was met with a “hug,” commentary about my motives and behavior were ongoing. The ongoing nature of this process—and the simultaneously ongoing nature of talk among participants—presented the third and perhaps most challenging ethical quandary.

Specifically, as the journal entry illuminates, I had failed to understand the role of the community as a “we.” Because I viewed the community as simply a place from which I could recruit individuals, I hadn’t adequately considered or prepared for the role that members took in influencing one another, and how that might impact my interactions with individual participants. Ultimately, the initial thread generated comments for approximately two months, during which time participants discussed the merits of participating, posted updates following their interviews, and commented on their experiences. These comments were overwhelmingly positive; for instance, one participant wrote, “I did it and she was great to talk to, questions were awesome, and I got my gift card immediately after.” Another participant wrote, “The more we can share what we believe—the more people may understand why we make the decisions we do about vaccines!” This represents what I recognize now as a crucial shift; whereas initially I was viewed as someone out to persuade them to rethink their beliefs and behaviors, I became someone to be persuaded or convinced. In some ways, this was an ideal position.

At the same time, however, these posts were an acute reminder that my offline communication with participants would likely be discussed online. I was especially cognizant that the perception that I was “pro-vaxx” could threaten my ability to recruit new participants. However, my commitment to transparency and equalizing power relations required that I be honest and forthright about my own perspective and choices. Surprisingly, no comments on the forum itself asked me to explicate my own stance toward vaccines, nor did the first four participants I interviewed. The fifth participant, however, brought it up at the conclusion of the interview. I had mentally prepared for the question, but still felt anxious as I explained that I had some doubts but had ultimately chosen to vaccinate my son according to the recommended schedule. I stressed that I was just trying to understand why others made a different choice. A memo I drafted following the interview notes my anxiety: “Not sure if I just blew it—concerned that she will ‘out me’ as pro-vax on the forum and lead others to question my motives.” I had similar conversations with a number of other participants.

—1
—0

Ethics of Representation in RHM Research

Despite my concerns, however, these conversations were not—to my knowledge—recounted online. Ultimately, despite the unanticipated ethical challenges presented by this ongoing online dialogue, the comments and conversations it spurred helped me to establish the trust I had failed to gain earlier on.

Lessons for RHM Research

This essay has explored some specific ethical challenges posed by the process of recruiting from online spaces, and especially from communities that are distrustful of researchers. I conclude now with four lessons I take away from this experience. I am hopeful these might prove helpful for RHM scholars who consider using this practice in their research design, particularly as they work to listen to and incorporate the voices of skeptical populations and/or populations with alternative health beliefs and practices.

First, this essay would not have been possible if not for the reflexive journal I kept during the research process. I had considered journaling as an important strategy in enhancing the rigor of my findings (by making clear the assumptions and positionality that shaped my analytical choices). I see it now as an important ethical practice in itself. That is, in addition to transparency, the reflexive journal afforded both the space to reflect and act during the research process, and the kind of detailed, process-level records that are necessary to adequately recall and draw lessons from the experience after the fact. Accordingly, RHM researchers should consider the reflexive journal as both helpful to the analytical process and as an important strategy in the ongoing process of becoming/being ethical researchers.

Second, and more specific to the ethics of interacting with participants, I should have made clear in my email to the website administrator that I did not want the message posted without subsequent approval from the forum moderator. While IRBs, website terms of use, and administrators may dictate the technical parameters of access to an online community, there are additional ethical obligations to participants and there should be no overriding approval or exemption from this process. Researchers should afford community members the choice to allow a researcher into an online community, whether to observe, engage, or recruit. Beyond the ethical imperative, the pragmatic consequences of not doing so can impact trust and the research process in detrimental ways.

Carrion

Third, I had assumed that the more intimate—and controlled—environment of the interview itself would be the time I might be called on to establish my credibility and motives as a researcher. While I had anticipated fielding questions from potential participants, including about my own perspective, I thought these exchanges would take the form of a thoughtfully considered, edited, and personalized email dialogue. These are luxuries not afforded by an online forum that can quickly be overwhelmed by problematic comments. Accordingly, when using online spaces to recruit for offline data collection, researchers should consider the real-time, immediate response that may be required in order to facilitate researcher-participant relationships and prevent negative responses from derailing the process.

Finally, something that seems so obvious now, didn't then: My plan to talk to each participant offline and individually didn't prevent them from talking about (and to) me online and collectively. This speaks to the need for researchers to consider how communication among potential participants may shape the trajectory of the recruitment and data collection processes. Ultimately, RHM researchers—and especially those who study health/medical controversies and populations potentially stigmatized by their health beliefs or practices—have much to gain from engagement with online communities but must also be fully prepared to respond to questions, maintain transparency, and acknowledge positionality as they do so.

MELISSA L. CARRION (PhD, Purdue University, 2014) is an assistant professor of rhetoric and writing in the Department of English at the University of Nevada, Las Vegas. Her research focuses on rhetoric and technical communication, especially in the context of health and medical controversies.

References

- Bednarczyk, Robert A., Tate, Tyler, Opel, Douglas J., & Omer, Saad B. (2017). The church, the state, and vaccine policy. *The American Journal of Bioethics*, 17(4), 50–52.
- De Hertogh, Lori Beth (2018). Feminist digital research methodology for rhetoricians of health and medicine. *Journal of Business and Technical Communication*, 32(4), 480–503.
- Harding, Sandra (2004). Introduction: Standpoint theory as a site of political, philosophical, and scientific debate. In Sandra Harding (Ed.), *The feminist standpoint theory reader: Intellectual and political controversies* (pp. 1–15). Routledge.

—1
—0

Ethics of Representation in RHM Research

- Hesse-Biber Sharlene N. & Leckenby, Denise. (2004). How feminists practice social research. In Sharlene Hesse-Biber and Michelle L. Yaiser (Eds.), *Feminist perspectives on social research* (pp. 209–226). Oxford University Press.
- Kirsch, Gesa E. (1999). *Ethical dilemmas in feminist research: The politics of location, interpretation, and publication*. State University of New York Press.
- Kolodziejski, Lauren R. (2014). Harms of hedging in scientific discourse: Andrew Wakefield and the origins of the autism vaccine controversy. *Technical Communication Quarterly*, 23(3), 165–183.
- Lawrence, Heidi Y. (2020). *Vaccine rhetorics*. The Ohio State University Press.
- Lawrence, Heidi Y., Hausman, Bernice L., & Dannenberg, Carol J. (2014). Reframing medicine's publics: The local as a public of vaccine refusal. *Journal of Medical Humanities*, 35(2), 111–129.
- Lindlof, Thomas, & Taylor, Bryan (2002). *Qualitative communication research methods*. Sage.
- McKee, Heidi A., & Porter, James E. (2009). *The ethics of internet research: A rhetorical, case-based process* (Vol. 59). Peter Lang.
- Navin, Mark C., Wasserman, Jason A., Ahmad, Miriam, & Bies, Shane (2019). Vaccine education, reasons for refusal, and vaccination behavior. *American Journal of Preventive Medicine*, 56(3), 359–367.
- Opel, Dawn S. (2018). Ethical research in “Health 2.0”: Considerations for scholars of medical rhetoric. In Lisa Meloncon and J. Blake Scott (Eds.) *Methodologies for the rhetoric of health & medicine* (pp. 176–194). Routledge.