Abstract
Research in science and technology studies has analyzed how patients’ groups engage in practices that connect biomedicine and patient experience in order to become involved in the shaping of biomedical research. However, there has been limited attention to the affective dimensions of such practices. Based on ethnographic fieldwork with a gynecological cancer patients’ group in Sweden, this article focuses on practices that aim to influence researchers and research institutions to prioritize biomedical gynecological cancer research. It analyzes how “affects” are woven through these practices and pays attention to the entanglements of affects, biomedical research, and lay experience they involve. The article explores the relation between the gynecological cancer patients’ group and biomedical research as a set of material-semiotic practices of “moving evidence.” These practices of moving evidence (1) enact gynecological cancer as under-researched; (2) collect and produce new “evidence”; (3) “mobilize” the evidence at public events, in interactions with biomedical researchers, and in different online settings; and (4) entangle affects with biomedical and

Lisa Lindén

1Department of Sociology and Work Science, University of Gothenburg, Sweden

Corresponding Author:
Lisa Lindén, Department of Sociology and Work Science, University of Gothenburg, Box 720, 405 30 Gothenburg, Sweden.
Email: lisa.linden@gu.se
experiential evidence to enact (a lack of) gynecological cancer biomedical research as a matter of concern.

**Keywords**  
gynecological cancers, affects, evidence, biomedical research, patients’ groups, entanglements

**Introduction**  
It’s 8.30 a.m., late August. I’m sitting in a seminar room at the Swedish Cancer Society (SCS) with twenty politicians, journalists, researchers, and patient advocates attending a research seminar organized by the patients’ group “The Gynae Cancer Group” (GCG). It is about links between severe stress and cancer. The GCG “strongly believes that knowledge saves lives,” says board member, Karin, to introduce the seminar. She tells us that the seminar is the board member Alzena’s idea, but that Alzena feels too emotional to introduce it herself. Therefore, Karin reads out loud what Alzena has written. She reads that Alzena’s mother passed away of ovarian cancer two years ago. During her mother’s sickness, Alzena thought a lot about what had caused the cancer. Was it a virus, pesticides, or the fact that her mother lost a newly born child soon after she lost her husband? When she discovered the biomedical research on how trauma increases risk for cancer, she became increasingly convinced that the trauma her mother had been through had influenced the diagnosis and prognosis.

During the seminar, one of the two researchers presenting draws upon her research group’s study of severe stress and cancer. Based on randomized controlled trials (RCTs) using mouse models to study a connection between stress and breast cancer metastases, she explains that “stress accelerates cancer by helping cancer cells in the body” and “stress stops cancer treatment from working.” But she states there’s some good news; there’s an existing treatment that helps, beta-blockers. “Blocking stress stops cancer spreading,” she says.

Karin ends the seminar by emphasizing that the GCG hopes that Swedish researchers will “team up” with the researcher to research connections between severe stress and, especially, ovarian cancer. Before I leave the seminar, I talk with the board member Linda, who also lost her mother to ovarian cancer. She talks enthusiastically about the seminar and says “give people beta-blockers now!” and laughs.

Field Note (August 28, 2018)
The above field note was written while I attended a seminar on severe stress and cancer organized by the patients’ group I call the “GCG.” At the seminar, biomedical research about beta-blockers was enacted by both the researchers and the patient advocates as having the potential to save lives. The presentation of the research was framed by Alzena’s emotions as a bereaved cancer relative through her attempts to make meaning of her mother’s diagnosis as she searched for an answer to why her mother had developed and died from ovarian cancer. In an interview, Alzena told me she was with her mother throughout the treatment process. “I have, you know, seen it all from the start to the end, I know how it is,” she said. Her distress at what she had witnessed as she accompanied her mother was clearly evident as she became visibly upset and started crying. She explained that she read cancer research during her mother’s treatment, and it made her realize that gynecological cancers are not a research priority. She said this had made her angry: “I got angry, and when I get angry, I want to do something.” Doing something meant she got involved in the GCG to push for more biomedical gynecological cancer research.

As exemplified within the seminar on stress and cancer and in Alzena’s account of her patient advocacy, the GCG’s involvement with biomedical research is intimately entangled with affect and emotions. While a considerable amount of research in science and technology studies (STS) has focused on how patients’ groups entangle biomedicine and patient experience in order to become involved in and to shape biomedical research (Novas 2006; Panofsky 2011; Wehling, Viehöver, and Koenen 2015), considerably less attention has been paid to how affect and emotions—what I will term “affects” (Zeiler 2020)—participate.

Research about the relation between patients’ groups and biomedicine has considered the making of collective identities, the democratization of health, the material production and mobilization of knowledge, and the relationship between professionals and laypeople (Wehling, Viehöver, and Koenen 2015). This research has explored how patient advocates influence biomedical research by making themselves part of networks of expertise, such as by forming social relationships with scientists (Panofsky 2011). Through such networks, patients’ groups engage in collaborative research practices “in the wild” (Callon and Rabeharisoa 2003) that aim to “speed up” the arrival of new therapies (Novas 2006). Moreover, Rabeharisoa, Moreira, and Akrich (2014, 111) have suggested we consider current forms of patient activism as a form of “evidence-based activism,” through which patients’ groups “elaborate evidence on the issues they deem important to address both at an individual and at a collective level.”
In the above research, there is a strong emphasis on the material (Callon and Rabeharisoa 2003), epistemic (Rabeharisoa, Moreira, and Akrich 2014), and temporal (Novas 2006) dimensions of the relation between patients’ groups and biomedical research. In this article, I consider how such dimensions are inseparable from—entangled with (Barad 2007; Latimer and Miele 2013)—affects. Drawing upon one year of ethnographic fieldwork, I focus on the activities related to biomedical research that the GCG initiates and participates in. I attend to activities that aim to influence researchers and research institutions. I analyze how affects are entangled with, and participate in enacting, what the GCG defines as its “cause” of “demanding more research” about gynecological cancers in Sweden. Furthermore, by taking my cue from the focus on “evidence” in the work on evidence-based activism (Rabeharisoa, Moreira, and Akrich 2014), I explore the GCG’s practices of enacting evidence to support this cause, and how such practices entangle evidence with affects. This evidence is based on biomedical knowledge and lay experience and is materialized in and through the GCG’s practices.

In the GCG’s practices, evidence and affects are entangled with movements. For example, within the seminar on stress and cancer, biomedical evidence was moved from the laboratory setting to a public setting of patient advocacy. Through this movement, the evidence was transformed from being about a connection between severe stress and cancerous metastases in mice to be about a potential connection between severe stress and ovarian cancer. Moreover, the evidence was enacted as moving in an affective sense, linked to lay experience from Alzena’s account as a bereaved cancer relative. Also, the evidence, including biomedical research and lay experience, propelled excitement as exemplified through Linda’s enthusiastic talk about beta-blockers as a potential cancer therapy. My fieldwork demonstrates that a moving of evidence in space and time is, in the practices of the GCG, entangled with affective sensitivities toward, for example, bereavement, anger, and excitement. To sensitize the analysis to such entanglements, I pay attention to how affects are enacted in, and participate in enacting, sets of heterogeneous, material-semiotic relations in which humans and nonhumans are entangled.

In what follows, I first consider the role of affects in studies of patients’ groups’ shaping of, and involvement in, biomedical research. To describe the importance of affects in scientific practice, I go on to discuss studies of affects in scientific work and in public engagement with science, and from there I explain the analytical perspectives on “affects,” “entanglements,” and “evidence” upon which I draw. I then describe and discuss the empirical
data the article draws on to show how enactments of evidence are entangled with affects in the GCG’s practices. Finally, I summarize my findings and discuss the case of the GCG in relation to broader questions about the relations between patient activism, biomedical research, and affects.

**Affect and Emotion in STS Research on Patients’ Groups’ Involvement in, and Shaping of, Biomedical Research**

Since the rise of patient movements around HIV/AIDS in the 1980s (Epstein 1996) and breast cancer in the 1990s (Klawiter 2008), STS scholars have taken an interest in how patient advocates mobilize to transform biomedical research. This research has primarily paid attention to epistemic, material, and temporal dimensions. In this section, I illustrate this by discussing work that has centered on “concerns” and “hope” and I explain how my article draws upon, yet extends, this research.¹

Latour’s (2004) notion of “matters of concern” has frequently been used to describe how patients’ groups turn diagnosis areas into issues in need of public attention (Panofsky 2011; Rabeharisoa, Moreira, and Akrich 2014). As has been discussed outside of the context of patients’ groups, “concern” can be understood as an “affective state” (Puig de la Bellacasa 2017) that denotes “worry, attentiveness, and thoughtfulness” (Martin, Myers, and Viseu 2015, 629). However, in the research on patients’ groups, “concern” is not primarily analyzed as an affective phenomenon. For example, in their work on a French patient association of patients with muscular dystrophy, the Association Française contra les Myopathies (AFM), Callon and Rabeharisoa (2003) draw upon the notion to discuss the emergence of “concerned groups” and the construction of individual and collective identities. Relatedly, in the articles in the special issue on evidence-based activism (Rabeharisoa, Moreira, and Akrich, 2014), concerns are discussed as part of knowledge practices that entangle medical and experiential evidence. As one example, Akrich et al. (2014, 131) show how childbirth organizations produce and mobilize evidence to constitute childbirth as a “matter of concern” made up of “heterogeneous assemblages of people and the objects/issues with which they are concerned.” I extend attention to concerns in patient activism by focusing on how the practices of the GCG entangle affects and evidence in order to turn gynecological cancers into a matter of concern. Hence, I analyze concerns as not primarily an epistemic matter but also as an affective phenomenon.
Research that has analyzed the dynamics of hope in patient advocacies (Novas 2006; Langstrup 2011; Pinto, Martin, and Chenhall 2018) has explored the temporal and material dynamics of hope and provided insight into how hope for new therapies enrolls patients’ groups. That is, hope motivates groups’ involvement in, support for, and promotion of biomedical research as the most effective mode of gathering evidence for treatments. Notably, Novas (2006, 295) attends to how hope figures in patient activism as a way of shortening “the temporal horizons of biomedicine’s potentialities to develop cures or therapies.” While sharing Novas’s interest in how hope operates temporally, Pinto, Martin, and Chenhall (2018, 128) pay attention to its emotional dimension. By analyzing patients’ groups’ “emotional investment in the quest for cure,” they show how engagements with biomedical research can enact “false hopes” that lead patient advocates to feel “frustrated” or even “disillusioned.” I develop this further by discussing hope not only in terms of how it connects to other emotions but also how it participates in the enactment of evidence.

To analyze affects as part of entangled relations, I now turn to research that has analyzed affective entanglements in science and, from there, I explain my analytical approach.

**Entanglements of Affects, Biomedical Research, and Lay Experience**

STS scholars have recently explored how affective entanglements in the laboratory are vital for making scientific knowledge (Fitzgerald 2013; Latimer and Miele 2013; Kerr and Garforth 2015; Myers 2015). This work, as Parker and Hackett (2014) make clear, builds upon a long history of research that has challenged a vision of science as dispassionate and disinterested (Haraway 1988) and has examined the role of emotions such as love (Latour 1996) and wonder (Daston and Park 1998) in the doing of science and technology. For example, Myers’s (2015) study of molecular biology analyzed the affective entanglements of scientists and molecular models. Relatedly, Fitzgerald (2013) explored the emotional narratives of neuroscientists about their intellectual interest in neurobiological accounts of autism. He shows that their commitment to science can be understood as an “entangled relationship between intellectual and affective practices” (Fitzgerald 2013, 139). Similarly, research on science communication, such as science festivals (Davies 2019) and workshops with local communities (Michael, Wilkie, and Ovalle 2018), has shown that affects play a key role in how publics engage with science. For example, Davies (2019) attended to
the “emotion work” through which science is negotiated and resisted at science festivals. Taken together, this body of research makes clear that scientific practices in the laboratory and in the public sphere are permeated with affects.

In the above work, there are differences in how “affect” and “emotion” are discussed. Many argue for a conceptual distinction between these notions. Affect is understood as more-than-discursive intensities, like the sense of movement and sensation, and emotion as the social interpretation of such intensities (Latimer and Miele 2013). Drawing upon Hochschild (2003) and Ahmed (2010), others attend to emotions as experienced and circulated, linked to politics of selfhood, and as performative (Kerr and Garforth 2015; Davies 2019).

In my analysis, I make use of both these strands in specific ways. I attend to how affects are performative and “do” things (Ahmed 2010), such as how they are enacted in the GCG’s biomedical research–related practices to elicit interest in gynecological cancer research. Drawing upon sociological research on emotions, I analyze the presence of emotions in the GCG advocates’ accounts of their motivation to join and participate in the group (Jasper 2011) and their mobilization of evidence as a form of “emotion work” (Hochschild 2003). Through my fieldwork, I have also found it important to attend to less clearly defined affective qualities that exceed the naming of particular emotions by individuals (Latimer and Miele 2013). In attending to the performative effect of affective qualities such as laughter, tones, and movements at meetings and events, I make use of the notion of “affective atmospheres” (Anderson 2009). Atmospheres evolve from the assembling of “human bodies, discursive bodies, non-human bodies” (Andersson 2009, 80) but exceed those individual bodies. They are impersonal in that they emerge from collective situations, but they are often felt as intensely personal (Andersson 2009).

To hold the two perspectives on affect and emotions together, I use “affects” as an umbrella term for the phenomena of “emotion,” “feeling,” and “affect.” Moreover, I talk about “emotion” to refer to the expression of particular, named emotions, and “affective practices” and “atmospheres” to describe less clearly defined affective qualities.

As suggested above, the notion of “entanglement” is used frequently in both STS research on patient activism (Callon and Rabeharisoa 2003) and literature on affects in scientific work (Latimer and Miele 2013). The notion is used to describe “webs of relations” (Latour 2004) or “the inseparability of objects and agencies” (Barad 2007, 197). Drawing upon this, I use the notion to attend to the inseparability of the affective, epistemic, material,
and temporal dimensions of the GCG’s practices of enacting evidence and promoting gynecological cancer research. The notion allows me to pay close attention to how affects participate in the production and mobilization of evidence and are part of forms of evidence. In particular, I attend to what entanglements of biomedical research, lay experience, and affects enable the GCG to do: how such entanglements allow for the enactment of forms of evidence.

In using the notion of “evidence,” I follow Rabeharisoa and colleagues (2014, 115) to denote “the selection and articulation of knowledge statements” that “aims at providing robust knowledge on how patients’ and activists’ conditions or situations ought to be understood and treated.” “Knowledge statements” can be based on biomedical knowledge as well as lay and personal experience. As McKevitt (2013) shows, in the context of patient engagement, “experiential evidence”—that is, evidence based on personal, lay, experience—is frequently called upon by both advocates and professionals as a specific form of evidence that promotes the legitimization and institutionalization of patient involvement in medicine (McKevitt 2013, 117). As the very notion of experiential evidence suggests, in a context of patient activism, lay experience and evidence are in many ways entangled with one another. Drawing upon these insights, I use the notion of “evidence” to analyze the knowledge claims that are enacted and materialized in and through activities like the stress and cancer seminar, the writing of popular science summaries, and interviews with scientists. Here, my use of the notion of evidence is similar to how Akrich et al. (2014) analyze childbirth organizations’ surveys and popularization of research as a production and mobilization of evidence. Yet, as discussed above, in the GCG’s practices, evidence is entangled not only with lay experiences and biomedicine but also with affects and movements. Read in this way, the doing of evidence becomes a multilayered, material-semiotic practice of what I call moving evidence.

The concept of moving evidence captures how evidence is moved in time and space and how it is made to be moving in an affective sense. Utilizing the concept, I analyze the practices through which evidence is put into motion by humans and nonhumans and how evidence, in turn, moves humans and nonhumans (Latimer and Miele 2013). For example, and as I will show, pharmaceuticals such as beta-blockers participate in practices of moving evidence. Hence, my analysis below develops the notion of moving evidence to show how the GCG’s identification of a cause, and their enactment of evidence, is intimately entangled with affects.
Methods and Case

This article draws upon an ethnographic project exploring the practices of gynecological cancer patients’ groups and is based on one year of fieldwork online and off-line (April 2018 to April 2019). The project has been granted ethics approval. To allow for anonymity, I coded names and the organization. The empirical material consists of fourteen interviews with board members, ex-board members, and volunteers; twenty internal board and working group meetings (both in place and on Skype); six seminars; two webinars where I participated from the broadcasting space; and two patient council meetings. The data set also comprises an extensive amount of online material from the organization’s web page and social media channels as well as diverse documents such as newsletters and popular science and media debate articles written by the organization.

The material has been analyzed using two rounds of thematic coding, where an inductive coding round was followed by a more theoretically grounded round. First, codes such as “cancer experience” and “lack of knowledge on gynecological cancer” were created. During the second round, codes such as “evidence” and “affects” were introduced.

The GCG was established in 2007. It is focused on providing knowledge about gynecological cancers to citizens and professionals, influencing research and health care, and providing support to women with cancer and their relatives. In this article, I focus on one part (by no means the largest) of their work, namely their stated cause of “demanding more research.” During my fieldwork, the group active in the GCG consisted of between eight and twelve board members and around four to six members in their different working groups (consisting of board members and sometimes additional people). The organization has approximately 1,300 members.

In Sweden, patient associations are most often funded by the state, but such funding is conditioned on associations following a structure of national alliance with local chapters. As the GCG functions as a group without local chapters, it stands outside such funding (a decision my informants explain as they don’t want to “get stuck” in bureaucracy; they want to focus on their causes). While the GCG is increasingly participating in top-down forms of participation, like governmental patient councils, a large number of their activities take the form of “uninvited participation” (Wehling, Viehöver, and Koenen 2015). In other contexts, such as in the UK, it is becoming increasingly common that professional staff manage patients’ groups (Baggott, Allsop, and Jones 2014), but this is not the case with the GCG. Its board members and volunteers have personal experience of cancer or cancer
risk (experiences of high-risk cytological abnormalities or a BRCA mutation) and/or are relatives to cancer patients. The majority work part time or full time in another profession and engage in the GCG during evenings and weekends. Their professional backgrounds vary, but the majority have a university degree, working in research, health care, and management. The group consists of people in their twenties to senior citizens, and all involved are women.

**Practices of Moving Evidence**

When analyzing the data, three modes of moving evidence emerged: (1) identification of a cause, (2) collection and production of evidence, and (3) mobilization of evidence. I will focus on examples of these modes of moving evidence that, in their different ways, suggest the importance of attending to entanglements of affects and evidence in patients’ groups’ involvement in, and shaping of, biomedical research.

**Identifying a Cause: Anger, Shame, and a Feeling of Under-prioritization**

When Karin introduced the stress and cancer seminar, she said that “ovarian cancer is underfinanced” and that the SCS, the largest funder of cancer research in Sweden, has decided to prioritize ovarian cancer through a special research call. However, she did not say that the GCG recently has worked extensively to influence the SCS to prioritize ovarian cancer as part of its increasing investment in cancers with very high death rates. Before I describe this, it is important to detail the practices of the GCG that identify gynecological cancers as underfinanced. As I will show, these practices are intimately linked to emotions.

In the interview where Alzena explained that she “got angry,” she said:

> It was my feeling that gynecological cancer was very under-prioritized and that made me angry, and then I wanted to do something. […] When I heard the doctors, it was like “yes, we have tested this on this cancer type, now we can also test it on gynecological cancer, or on ovarian cancer, and then we’ll see.” It was a bit like that. When I read … As I have a research background, I also read a lot of research articles and then it was a lot like “we have proved that this works for this and this, now we can test it for gynecological cancer.” […] It wasn’t, you know, the main priority. Instead, it sort of came far down the list.
Alzena’s account is similar to those of many of my other informants. Linda, for instance, explained to me that during her mother’s ovarian cancer treatment, she experienced problems with current gynecological cancer care; she felt that “oh my god, it must be possible for it to work better than this!” She told me that she was with her mother at the hospital and had experienced how powerless patients and relatives can feel. She linked this to an under-prioritization of ovarian cancer: “ovarian cancer is under-researched, and we try to put it on the map.”

Linda and Alzena describe feeling emotions of powerlessness and anger because the gynecological cancer care isn’t good enough. In their accounts, powerlessness and anger translate into agency and action; the emotions facilitated them joining the GCG. While “powerlessness” typically would be considered the opposite to agency, in Linda’s account, an experience of powerlessness facilitated action. Linda did not want others to have to feel as powerless as she had. Following Ahmed (2010), it is here possible to understand both “anger” and “powerlessness” as generative and performative, as opening up for action. As I noted above, Alzena described that getting angry had made her read biomedical research. Her experience of her mother’s ovarian cancer moved her to read research, which in turn moved her: through the reading, she felt more certain that gynecological cancers are under-prioritized. Here, the experience gained from being closely involved in her mother’s treatment process, her anger about the situation, and the evidence acquired by reading biomedical research are entangled. This entanglement of emotions, experience, and biomedical research enabled Alzena to identify gynecological cancer as under-prioritized and moved her—in an affective and spatial sense—to act. That is, the entanglement made Alzena (and Linda) act differently, by joining the GCG and by collecting evidence that she also brings with her to spaces such as the stress and cancer seminar. This exemplifies how practices of moving evidence are both affective and spatial phenomena. This is comparable to how Fitzgerald (2013) describes researchers’ scientific interest in specific areas of biomedicine as traced to a feeling of being “hit in the stomach” by, in his case, autism. Being “hit in the stomach” by ovarian cancer, and by the evidence from the research she read, Alzena was moved affectively, and this also moved her spatially to push for ovarian cancer research.

The board member Caroline, whose mother has advanced ovarian cancer, emphasized that she wanted to be involved in the group as “so few people knew about ovarian cancer and I guess I was irritated about that.” “I was super angry that my mother’s cancer was detected so late,” she continued and stressed that “more research is needed in Sweden on it.” Thereby
Caroline linked her mother’s late diagnosis to a lack of research on ovarian cancer. She said instead of “sitting home and being super angry that women [with ovarian cancer] are detected so late,” it was important for her to do something about it, so she joined the GCG. In describing how irritation and anger made her get involved in the GCG, her engagement can be understood as entangling emotions with her experience as a cancer relative and with (a lack of) biomedical research. As with Alzena, this entanglement allowed her to identify gynecological cancer as under-prioritized.

That gynecological cancers are not well-known was noted by many of my informants to explain why they are under-prioritized in biomedical research. This was often linked to “shame” or to “a stigma.” Alzena, for example, said, “it’s still a little shameful to have gynecological cancer” and explained:

[...]. This is really a low-status cancer that you don’t talk about. It’s hidden. [...]. Within health care it’s under-prioritized. Within research, underfunded. [...] It’s about bleedings and discharges and, yes... It’s a problem you don’t talk about at the coffee break.

As Alzena did here, many of my informants connected the status of gynecological cancer (“low-status cancer”\textsuperscript{5}) with emotions of shame, something they in turn linked to the location of these cancers in women’s reproductive and sexual organs. For example, the board member Mia said that it is a low-status cancer since “[i]t’s about, you know, sexual organs, purely female organs and I don’t think it’s interesting enough for the professionals.” Similarly, the volunteer Malena argued that it is a low-status cancer and stigmatized as it is “difficult to talk about sex, sexual organs, and sexuality, problems with the sexual organs.” Ultimately, the notion of low-status cancer and emotions of shame were evoked to explain why gynecological cancers are under-prioritized. As is clear from accounts of the early HIV/AIDS (Epstein 1996) and breast cancer (Klawiter 2008) movements, the challenging of processes of shaming can be an essential part of patient activisms mobilizing against stigmatization and for visibility and societal change. Similarly, in the GCG’s practices, shame does not “close down” action. Instead experiences of, and knowledge about, shaming are performative in how they, as a form of evidence of an under-prioritization of gynecological cancer, enable political action.

Identifying gynecological cancers as under-prioritized, low status, and shameful enables the GCG to enact a vision of societal change in which gynecological cancers are higher status and higher priority and enact a
cause of “demanding more research.” Through this cause, the GCG moves biomedical and experiential evidence into the public realm, something that can be understood as a turning of (evidence about) gynecological cancer into a matter of concern. This opens up a space to move—affectively and spatially—others to become concerned about the under-prioritization of gynecological cancers. As I will show, in such practices, “anger” is transformed into action, partly through investment in “hope.”

**Producing Evidence, Enacting Hope**

One of the researchers at the stress and cancer seminar emphasizes that there is weak evidence that stress leads to cancer but it is stronger for some cancers, such as cervical cancer. “Bereavement is associated with an increased risk of human papillomavirus (HPV) infection and cervical cancer,” she states and explains that she has researched how “the loss of a significant other” increases the risk. Neither she nor the other researcher brings up ovarian cancer.

Alzena asks whether patients from Sweden can be included in RCTs on severe stress and cancer. One of the researchers answers that she is open to “team up” with research groups in Sweden. Karin brings up the SCS’s investment in ovarian cancer research as suitable for this and says that she will raise this with them. (Field Note, August 28, 2018)

At the seminar, members from the GCG encouraged research on a connection between severe stress and ovarian cancer. By putting together two not yet linked elements—ovarian cancer and research on stress and cancer—the group, in fact, produced evidence supporting research on this potential connection. When doing so, I (and many others in the room, I suspect) thought about Alzena’s story of her mother’s loss of a child. Her story became a form of experiential evidence supporting the need for funding research on a connection between severe stress and ovarian cancer. Biomedical and personal evidence became entangled; I understood the researcher’s focus on “the loss of a significant other” through Alzena’s story. Thus, the GCG enacted evidence on stress and cancer as something affectively moving. This framing of the research that entangles the biomedical research on stress and cancer with Alzena’s story can be understood as a “staging” of emotions that facilitates mobilization to put ovarian cancer on the research agenda, similar to Jasper’s (2011, 292-93) description of “emotional displays” used by activists to focus attention toward their political cause.
The group also enacts evidence in the media. This includes, for example, writing and circulating debate articles, press releases, and summaries of events. As I will discuss below, through activities such as these, evidence is not only turned into something affectively moving but is also moved spatially. For example, after the stress and cancer seminar, the group moved the evidence from the stress and cancer seminar to their home page and wrote:

[The researcher’s] studies show that treatments, like immunotherapy and chemotherapy, are ineffective because of the adrenaline. [. . .]. **But there’s hope!** Through increased knowledge about what happens in the body during stress, it’s also possible to find solutions. [The researcher’s] advanced studies show that the simple and already known pharmaceuticals beta-blockers can stop the adrenaline and, thus, suppress the growth of metastases and make the treatment effective again. [. . .] **Currently, the Swedish Cancer Society has invested in ovarian cancer research for a few years. We would like to influence clinics to get interested in conducting a study on how beta-blockers affect the growth of metastases in ovarian cancer.** (The GCG’s home page, September 2018, bold in original)

Through this summary, the group moved the evidence about stress and cancer to an online setting and, when doing so, enacted evidence stating a need for research on stress, beta-blockers, and ovarian cancer. As their home page is used by both expert and laypeople, this is an important space for enacting evidence and for enacting a lack of ovarian cancer research as a matter of concern. Moreover, for the group, and as is often brought up at internal meetings, one important aspect of publishing summaries of biomedical research and other related activities is to provide hope to patients and their relatives. “There’s hope,” as the group wrote in the above summary. Further down in the summary, discussing beta-blockers as a potential solution to stress, beta-blockers are presented as central for why there is hope. This enactment of hope can be understood as a political tool mobilized by the GCG to “energize” researchers and research institutions to prioritize ovarian cancer research.6

Drawing on work on the social production of ignorance in science, scholars such as Frickel et al. (2010) and Jain (2013) show how hopeful attention to potential cancer therapies—for example, via patient advocacies—facilitates ignorance of other dimensions of cancer, such as societal causes and responsibilities, and scientific uncertainties. When the evidence from the stress and cancer seminar was spatially moved online via the
summary above, specificities concerning scientific uncertainties were lost; such as that one of the scientists said that evidence that stress leads to cancer is weak and that the scientists did not mention ovarian cancer. Hence, through the attention to “hope,” potentially complicating uncertainties and specificities were lost. Similarly, at internal meetings of the GCG in the months after the seminar, beta-blockers were discussed in terms of how their use could be promoted, as “what can be done” (Karin). While the GCG sometimes stressed the need for societal preventive efforts that can decrease people’s stress, I noticed how societal aspects often became marginalized in relation to beta-blockers. Beta-blockers were frequently enacted as “the solution” to the problematic relation between severe stress and cancer, and excitement animated discussions about them. For example, at a meeting about their 2019 evening seminar, the presence of beta-blockers in people’s talk enacted an affective atmosphere that facilitated these pharmaceuticals as “the solution”:

“Beta-blockers to the people, I feel!,” Linda excitedly asserts. Karin responds that “it is a bit sensitive, though.” She stresses that the link so far only exists in studies on mouse models, and that the researcher cannot recommend use of beta-blockers yet. Yet, she continues, “[beta]blockers’ side effects are well-known” and she mentions nightmares as one such side effect. “I take nightmares any day!” Linda replies instantly. “Yes, me too” and “we’ll take that!” people respond excitedly and they laugh loudly. In referring to their upcoming evening seminar, Karin concludes that “we need to include this [research] with stress, cancer, and beta-blockers.” (Field Note, September 1, 2018)

In saying, with laughter, that they would take nightmares “any day,” the group compared beta-blockers’ side effects favorably with their experiences of cancer. In doing so, Karin’s impasse that the issue of beta-blockers is “a bit sensitive” was quickly forgotten, and scientific uncertainties and specificities were thereby made absent. When the conversation steered toward beta-blockers, the excitement was instant, noticeable through the loud laughter and excited voices. Understanding the laughter and excited voices as an affective practice allows me to analyze entanglements of affective atmospheres and pharmaceuticals in practices of moving evidence. In emphasizing that they need to include the research on beta-blockers at their evening seminar, it is clear that the beta-blockers were not only a cause of excitement and laughter but that they also moved the focus of the group’s work.

Beta-blockers exemplify entanglements of hope and pharmaceuticals in patients’ groups’ engagement with science and in their enactment of
evidence. These pharmaceuticals participate in practices of moving evidence; they affect people and are, in turn, affected themselves in how they are enrolled in producing evidence used to promote more biomedical research. In such practices—not least when they include people who themselves are affected by cancer—it makes sense to present beta-blockers as “what can be done.” In the face of experiences of powerlessness and anger, the appeal of solutions that provide hope and make problems “fixable” is understandable. However, because of the pharmaceuticals’ intense affective force, they could marginalize other possible ways to respond. Pols (2014) stresses that there is a risk that patients’ groups’ increased involvement in biomedical research marginalizes their previously strong focus on care practices aiming to improve ways of living with chronic illness. In relation to the strong affective appeal of pharmaceuticals, this is important.

The production of scientific knowledge is conditioned by particular ways of seeing: “by looking in certain ways one leaves unexamined other ways of understanding” (Kleinman and Suryanarayanan 2013, 495). However, my analysis suggests that patient advocates’ production of evidence on potential therapies might also be conditioned on particular ways of feeling science that facilitates ignorance of existing scientific uncertainties. As I described above, specificities in the scientists’ presentations at the stress and cancer seminar were marginalized when the GCG moved the evidence from the seminar to other spaces (online platforms, internal meetings), and when excitement intensified around beta-blockers as a potential cancer therapy. As this demonstrates, through affective entanglements of lay experience and biomedicine, there is a risk that advocacy practices attend to the potentialities of cancer therapies and not their uncertainties or problems. Hence, advocates’ investment in cancer therapies as objects of hope may not only allow for the production of evidence but also, simultaneously, of ignorance.

**Mobilizing Evidence and Emotion Work**

The GCG regularly interviews researchers and research officers. When being interviewed by the GCG in 2014, the chief research officer (CRO) at the SCS said that if we consider how many women have gynecological cancers, then “the gynecological cancer area is relatively underfinanced.” He stressed that since the connection between HPV and cervical cancer was discovered, the research finance for cervical cancer corresponds with incidence and mortality rates. This, he said, is not the case with ovarian cancer. This interview has become crucial for the GCG’s practices, frequently
referenced at events and in the media to support their call for more ovarian cancer research. In entangling mortality rates, ovarian cancer, and a lack of research, the interview is a material production of evidence supporting their cause. Caroline mentioned the interview with the CRO during an interview:

I think we should be really proud about that. I really think we were a strong driving force that they chose ovarian cancer...[...]. [W]e’ve constantly reminded them about that [the CRO] said [...] that ovarian cancer research is...the research that is ongoing is not in proportion to how many that die. [...] And that we have made him regret that he said that. [laughter] [...] We quote him very, very often.

As Caroline said, the GCG must constantly remind the CRO that he himself said that more ovarian cancer research is needed. Hence, the interview with the CRO becomes evidence that is subsequently mobilized. At internal meetings, the group has often joked about this as a matter of “rubbing it in”; a practice of repeating the same message again and again. To do so requires the GCG to be what Caroline formulated in an interview as “a pain in the ass.” She explained this as that they “don’t make it comfortable for people” and “don’t give up.” Relatedly, Karin described them as “terriers,” who “are always prepared” and “don’t let go or give up.” That they don’t give up is also one of the most frequent answers I have received when I have asked the group what distinguishes the GCG from other patients’ groups.

The descriptions of the group as pains in the ass and terriers were said by Caroline and Karin with laughter and in a joking tone. Similarly, that they “rub in” the message has been a source of laughter and humor at meetings. Rather than merely describing the group’s mobilization techniques, read alongside the laughter and humor, being terriers or pains in the ass suggests an affective practice that “binds” the group together, similar to how Parker and Hackett (2014, 562) describe humor as important for the creation of “collective solidarity” in research groups. My analysis suggests that this is equally important for patients’ groups’ engagement with biomedical research. The laughter and humor are indicative of a specific collective and affective attuning to the mobilization of evidence.

The importance of laughter and humor as affective practice can be further demonstrated. In interviews, several of the GCG representatives have talked about a specific “energy” in the group. For example, Caroline said, “the energy that all the people in the group have is completely amazing!” and the board member Hanna said being involved in the group is important for her as
“you get motivation and energy and a sense of community in a really great way.” As I have also experienced myself during their meetings, there is a specific atmosphere or “energy” in the group, where laughter and jokes are important for the enactment of the GCG as a collective.

At events and meetings, when I have observed representatives from the GCG interact with scientists, they have been friendly and enthusiastic. Moreover, they have emphasized that they are appreciative. For example, when a professor visited their board meeting in April 2019, Karin strongly emphasized that he was their “source of knowledge” and that they have learnt enormously from him. To be a terrier-in-practice, for the GCG, involves embodied navigation of different emotions: being forceful (“not giving up”), yet doing so by being friendly and enthusiastic. It is a practice that can be understood as “emotion work” (Hochschild 2003; Davies 2019) that requires the elicitation of particular emotions in accordance with the specific role of being a patient advocate.⁷ Therefore, such emotion work is also important for understanding the mobilization of evidence, for example, how the GCG has mobilized the interview with the CRO.

In relation to the theme of stress and cancer and the interview with the CRO, I have observed a practice of not giving up. After the stress and cancer seminar, during the upcoming months, the group sent e-mails to their research networks, encouraging research on stress and cancer. Moreover, as previously mentioned, while planning their 2019 public evening seminar, the theme of stress, cancer, and beta-blockers was frequently brought up as something to “hold on to” (Caroline). At the seminar, a presentation on stress and cancer by Alzena was included. Thereby they did hold on to the theme and moved the evidence on stress and cancer to this public space.

A practice of not giving up can be understood as a practice of repeating the same message, but doing so in a “sociable” (Panofsky 2011) manner that requires emotion work. This involves moving evidence to varied settings such as public seminars and online spaces. Evidence is transformed through such movements as it is enacted together with a demand for more gynecological cancer research. This is an affective practice that requires spatially moving the evidence alongside emotion work to enact a lack of gynecological cancer research as a matter of concern in a forceful, yet friendly manner.

Discussion

In this article, I have analyzed how the GCG identifies gynecological cancers as under-prioritized and under-researched and how it enacts evidence
to support this. Zooming in on the group’s practices of demanding more research, I have shown how its representatives read and write articles and summaries, interview concerned scientists, organize research seminars, and e-mail and talk with scientists to influence them to prioritize gynecological cancer research. By showing how affects are crucial parts of this work, I have paid attention to practices of what I have termed moving evidence: the multilayered affects, movements, and materialities involved in the engagement with, and enactment of, forms of evidence.

I have analyzed several aspects of practices of moving evidence. First, I have analyzed how entangling biomedical research and lay experience involved a feeling of under-prioritization, having a shameful low-status cancer and experiences of “anger,” “powerlessness,” and “frustration.” This identification of gynecological cancers as under-prioritized and shameful enabled these cancers to be enacted as a public issue and a matter of concern. Secondly, I have analyzed how this entanglement of biomedical research, lay experience, and affects was part of the GCG’s production of evidence, such as in the case of the intimate link between Alzena’s story of her loss of her mother and the biomedical research on stress and cancer. Thirdly, I have discussed how hope propagated affective attention to pharmaceutical solutions to cancer, like that of beta-blockers, and how this also enabled side-stepping scientific specificities and uncertainties. Finally, I have discussed the mobilizing of evidence as an affective practice that requires emotion work.

The case of the GCG’s involvement in and shaping of biomedical research priorities provides insights on the role of affects in patients’ groups’ engagement with biomedical research. My analysis allows for an approach that understands matters of concern as an affective practice of moving evidence. That is, turning diagnosis areas into matters of concern moves evidence into the public sphere and simultaneously transforms it into something affective that moves and is being moved by humans and nonhumans. Similarly, unpacking hope as affective practice enables research that understands how hope, when entangled with potential therapies and experiences of life-threatening disease, might gain strong force. More broadly, my analysis suggests the importance of attending to the role of affects in patients’ groups, both with regard to advocates’ accounts of their participation and the enactment of affects in patients’ groups’ activities. If affective dimensions are ignored, there is a risk that STS scholars reproduce a vision of patient engagement as a “rationalistic” voicing of concern, a vision of it as a primarily epistemic matter (and of epistemics as a non-affective matter). While hesitation to attend to affects perhaps has to do
with a fear of delegitimizing patients by positioning them as “emotional,” my study suggests that we instead need to take affects more seriously. In drawing together literature on affects in scientific work and work on patient activism, I suggest that, just as STS scholars have unpacked affects in the laboratory and in public engagement exercises, we need to attend to how affects matter in a multitude of ways for patients’ groups’ engagement with science.

In this article, I have suggested the concept of moving evidence is fruitful for the above endeavor. The notion makes it possible to further understand the relations between scientific practices in the laboratory and those “in the wild” (Callon and Rabherisoa 2003). On the one hand, the concept makes it possible to attend to forms of evidence as embodied, passionate, and situated practices that involve knowers who must affectively, materially, and spatially attune to the doing of specific evidence. On the other hand, it becomes possible to hold on to the affective specificities related to entanglements of lay experience and science in patient advocacies. By approaching patients’ groups’ engagement with biomedical research as entanglements of affects, biomedicine, and lay experience, it is hopefully possible to further understand such specificities.

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Notes

1. Outside a focus on biomedical research, a few science and technology studies (STS)-inspired studies have analyzed the role of emotions in health movements. See, for example, Montini (1996) and Klawiter (2008) on the “feeling rules” of breast cancer activism.

2. I use the notion of “lay experience” instead of “patient experience” as many of the Gynae Cancer Group (GCG) advocates have experience as cancer relatives and not patients.

3. All data are translated from Swedish into English by me.

4. People carrying a BRCA gene mutation are identified as being at high risk of breast and ovarian cancers.

5. I translate “fulcancer” into low-status cancer as this is the best possible option. However, if translated directly it would be “ugly cancer.” This to a higher extent denotes “fulcancer” as something shameful.

6. The GCG’s attention to hope connects the GCG’s practices to contemporary “cancer cultures” (Jain 2013; Brown 2015). The GCG also makes frequent references to “survivors” and “fighters”; notions linked to a predominant focus on empowerment in the context of cancer (Bell 2014).

7. Some of my informants have mentioned that they by professionals have been perceived as “uncomfortable” because they want to influence things “too much.” While I have not noticed such dynamics at events, this still opens up for reflections concerning the possible limits for what affects can be mobilized by patient advocates. It is likely that more “explosive” affects, such as being visibly angry or upset, would be met with skepticism from professionals, positioning patient advocates as “too emotional” and “too personal” and therefore not as legitimate experts able to participate “in the right way” in practices of democratic representation.

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Author Biography

Lisa Lindén holds a PhD in technology and social change from Linköping University. She is currently a postdoctoral researcher at the Department of Sociology and Work Science, University of Gothenburg, and a visiting scholar at the Centre for Science Studies, Lancaster University. She carries out qualitative case studies of biomedicine and public health, often with a specific focus on patient and public involvement, policy practices, and sexual politics. Her current research concerns gynecological cancer patient activism and politics of care.