Breast Cancer

Illness Narratives During COVID-19

Mehika Patel

Advisor: Philip Smith

A thesis presented in partial fulfillment of the requirements

for the degree of Bachelor of Arts

Department of Sociology

Yale University

2022

In loving memory of my mom, Kesha.

"All I ever needed to learn about life
was at her bedside in those days, sharing in hearing her last words
and watching the final struggles of her body." -Arthur F.

ABSTRACT

The COVID-19 pandemic sparked social overhaul and changed lives, perhaps forever. Breast cancer patients are among a number of vulnerable populations whose lives were especially disrupted. These patients have undergone changes in social life as the rest of the world has, in addition to disruptions to treatment courses. We already know much about living with breast cancer medically, and about patient outcomes during the pandemic. However, we know little of how patients make sense of and understand their illness. The pandemic has seen an increased popularity of online patient forums as sources of information and support. Forums are especially important as they provide a space for patients to speak honestly about their nuanced life experiences with the illness, beyond what is expected of them from nonpatients. This thesis seeks to understand breast cancer patient illness narratives during the pandemic, and in the process, show the value of understanding a patient's holistic experience beyond disease related talk. By creating topic models from forum comments, it sifts through mass amounts of textual data to pull the most relevant topics discussed in the forum. It found that illness is strongly relational. Patients assume different roles in their illness narrative depending on the context of disease and others. They also have different relations to their illness, others, and life itself. This research found a wealth of information can be gained from investigating how people discuss their holistic illness experience, and how much can be lost and harmed when forgoing these experiences.

Keywords: illness-talk, disease-talk, illness conceptualization, illness narrative, illness experience

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ACKNOWLEDGEMENTS

It is an honor and pleasure to express my deep gratitude and thanks for my advisor, whose guidance and feedback helped me not only complete this thesis, but has also helped me grieve and heal. I recall expressing to him that all I wanted from this thesis was to be proud of it. And his suggestions and recommendations guided me to a piece that I am not only proud of, but that was a process through which I have taken strides in learning to understand my own relationship with illness, death, and life. For that piece of healing and life, I cannot thank him enough. I also owe thanks to several others in Yale Sociology. To DUS Emily Erickson and TA Stephane Andrade, who provided feedback and countless sources of support. To other members of the Sociology Class of 2022, who were encouraging and always supportive.

I would also like to acknowledge and give my warmest thanks to several people without whom I would not have the heart and love that has motivated this thesis. Firstly, to the patients of these forums, for sharing their stories so honestly. To Nashirra, with whom I have gone through a majority of my sociology trials and tribulations. And to our larger friend group, that has consistently provided us with support, encouragement, laughter, and love. To my best friends, Thomas and Lindsay, who provided feedback and were by me through the entire journey that sparked the motivation of this thesis. To Danielle, for guiding me to my words, and for sharing in the heartache that has come in the process. To Ada, for providing both edits and meaningful appreciation for the work.

And lastly, to mom. You should not have had to be brave in the face of illness, but you were, for me. I owe you the world for this, for all the love you have poured into me, for the lessons you have taught me, and for leaving me with so much to live for in this life. Thank you.

INTRODUCTION

Over spring break 2020, at the suggestion of the CDC, Yale shut down campus to prevent the spread of COVID-19. I was now living at home again, with my mom. That spring marked the tenth anniversary of my mom's breast cancer diagnosis. I was seeing her every day again, as I had in high school. I regained a sense of the weight of her daily existence. The weight was made of doctor's appointments, countless medications, homeopathic juices, Candy Crush, violent medical therapies, sweet remarks from nurses and friends, painful cries at night, laughter in the company of television, cooking "from the heart", and me. But something had changed since I was last home. After the pandemic began, her doctors reduced the frequency of her non-urgent appointments. She seemed lighter. There was finally some relief from the painful side effects of monthly chemotherapies, talking to doctors, scheduling, and the blank boredom of waiting rooms.

One night that spring, she called me from my room to ask if there was something wrong with her. I was unsure how to respond to the dullness in her eyes and the fear in her tone. Nothing seemed "wrong" to me. But she was experiencing something strong enough to imagine it might have visible side effects that I would notice. I called an on-call nurse at her cancer center and recounted the incident. The nurse told her to drink water and to call back in 45 minutes to check in. It was clear the nurse didn't sense the severity and fear that both my mom and I held over the incident. And not having the words to explain the incident to the nurse felt even worse. Prior to the call, all my mom could communicate about the experience was that she had a weird feeling, almost inside her head, but not, and that her face felt droopy. This was not enough for the nurse or myself to understand the incident from my mom's perspective.

So in that 45 minutes, I sought desperately to help my mom articulate what it was that she had experienced. We had to find the right words so that the nurse could understand what had happened. I asked countless questions to probe the medical terminology that best described her experience. But there were no answers to be found. I asked her in resignation if there was absolutely anything she could say to help me understand. She finally likened it to the sensation she would have right before a seizure when she suffered from epilepsy as a child. "It felt like God was telling me it was about to come, so I would run to my mom and hug her." I felt defeat in not being able to comfort her as her mom did when she was younger. As an adult, my mom never expressed explicit fear of her sickness, holding a brave face while everyone she ever met praised her "strength." But either for lack of adequate medical terminology, or for her inability to relate her experience to any existing terminology, she was only satisfied with this answer. It was only likening the sensation to this scary childhood experience that could sufficiently describe what had happened to her that night.

In his book, *At the Will of the Body* (Frank, 2002)*,* Arthur Frank provides a way to categorize conversations about sickness. He says conversations related to someone's sickness are either disease oriented - "disease talk," or illness oriented - "illness talk". Disease talk objectifies bodily dysfunction, orienting the conversers to discussing only medicalized aspects of the sickness in a professional and collected manner. This orientation allows the patient to relate to the medical professional, for whom the body is "elsewhere", and can thus be objectified for study. Illness talk owns the holistic experience of sickness in all its forms. It recognizes that illness reshapes one's entire life. Frank also explains his frustration with the standard of disease talk when discussing illness, and finds valuable insight in illness talk. I now hold this sentiment as a standard.

No one knows what actually caused my mom's frightening incident. It could have been oncoming epilepsy. But it could have also been the metastatic tumor they later found in her brain, or countless other biological conditions. What I do know is that there was no way to even begin understanding the experience without her articulating it with illness-talk. She was describing a physiological sensation, sure. But it was only through the frame of considering her illness narrative, beginning as an ill and fearful child, that she was able to conjure the explanation. For the past decade, she became practiced in discussing her illness with doctors using disease-talk, and with others using a brave face. Her frame of reference with disease talk was medical terms, including physical sensations, bodily textures, observable biological routine. And wearing a brave face in front of others reduced her shareable experience to a strong determination and false fearlessness. All of these failed to make this one experience of hers communicable.

What changed in her ability to share this articulation of her experience was the prompt—from "what is happening to your body" to "give me absolutely anything," allowing her to think beyond disease-talk. I can only wonder how many such articulations have been lost in communication between medical professionals and patients. The nurse was only prompting my mom as she was professionally trained to. But my mom found only a loss for adequate words in these prompts. Perhaps if the nurse or I better understood how my mother thought about her illness, we would have sooner thought of more effective prompts to guide her descriptions and help us understand.

Understanding a patient's illness narrative, beyond just what is medicalized, offers us multiple dimensions of understanding them. In learning how patients make sense of and understand their entire illness narrative, we gain valuable insight in their experience and can better help them. But the mode of conversation we currently use to learn about patient experience

is only disease-talk, which neglects all other aspects of a person's experience while ill. During the pandemic, with lives overhauled, and millions of patients bombarded with fears, disruption, and isolation, we have possibly lost more understanding of illness narratives than ever before. With distance between patients and physicians expanding with reduced interaction, both have lost even the transient personal understanding of another person that is gained through frequent interaction. We have yet to understand how all of these changes have influenced whole patient illness narratives.

This thesis seeks to understand breast cancer patient illness narratives during the pandemic, and in the process, show the value of understanding a patient's holistic experience beyond disease-talk. Patients must feel that they have a free stage to wholly and honestly recount and reflect on their experiences in order to give us the explanations necessary to gain such a holistic understanding. But patients do not find this stage with their physicians or in their loved ones for their inability to sufficiently understand and relate to their experiences. However, they can find this stage among other patients, who share their experiences, fears, and hopes. Through a textual analysis of such a stage—online breast cancer patient forums—, this research will uncover the honest nuances of patients' holistic experiences during COVID-19. In examining this question, this research does not aim to glean specific patient outcomes, as there already exists research efforts investigating COVID-19 oncological medical effects. Instead, it aspires to demonstrate the wealth of useful information gained in understanding how patients make sense of how illness affects their entire lives, and not just their bodies, in the face of pandemic-induced social overhaul. Simultaneously, it aims to exemplify how we currently prompt patients to discuss illness, and what is lost and who is harmed in this process. What is at stake is a relational understanding of illness to the body, the disease, and others.

I begin with literature review on living with breast cancer and how it was disrupted at the onset of COVID-19. This review covers both theoretical understandings of illness, important to this analysis, and studies that contextualize the experiences of breast cancer patients during the pandemic. After detailing the quantitative methods used to model the data, I present and analyze the findings from the topic models. To conclude, I discuss limitations of the study, and urge future research in the arena of understanding illness narratives.

LITERATURE REVIEW

This literature review has two parts. The first part establishes what we already know about living with breast cancer, to lay the medical social theory on which I base my results analysis. After we begin to understand the experience of living with breast cancer, the second part considers the pandemic. The pandemic left millions of patients around the world overwhelmed with disruptions, fear, isolation, and stress. Though I stress the importance of non-disease-talk, it is essential to understand the disease aspects of illness, and build upon these with holistic learning. The second part of this literature review seeks to understand the disruptions in everyday life of patients, as well as the disease and medicalized aspects of patient experience, to lay social and disease context for patient narratives.

Breast Cancer Illness Experience

Defining Illness in a Social Context

Healthism and Medicalization

Theorizing and studying illness begins with discussing how illness and health are socially legitimized through two social mechanisms called healthism and medicalization. Defining these using *Crawford's Healthism and Medicalization of Everyday Life* will lay the theoretical foundation that will help us appreciate how illness experiences have been shaped and framed. Crawford defines healthism as a "preoccupation with personal health" for the "definition and achievement of well-being" (1980). Healthism has pervasively entered human life and continues to shape and guide our daily existence as both individuals and as a society. Without this

preoccupation, we cannot legitimize illness, as it must be contrasted with the ultimate priority of healthism–good health.

In the process of medicalization, patients assume a sick role, defined by theorist Talcott Parsons. He described illness as deviant behavior, the reason sick people are unable to fulfill their expected social roles (Parsons, 1964). The priority of Crawford's healthism, good health, is thus a state of social conformity, both biological and behavioral (Crawford, 1980). So long as a condition does not threaten social conformity in any important ways, it is not medicalizable. But when a condition, whether physical or otherwise, can be a threat to social conformity, it enters potential medicalization territory. The social implications of an illness become the legitimizing fact of the illness itself. Arguably the biggest threat to social conformity is death, the opposite of the image of vitality and good health. So when a condition is associated with death, or thought to be lethal, it is medicalized.

Social Framing of Illness

Chong and Druckman (2007) describe framing as the "process by which people develop a particular conceptualization of an issue" or change "their thinking about an issue" . Individuals will use however much they know about a subject and use their preexisting valuation of the subject to develop an opinion on it. Medicalization is used as a method to socially frame illnesses that are primarily experienced by those directly diseased. And as society sets its frame on an illness, so do patients as they learn about and come to understand an illness as their own. But how does framing shape illness experience itself? Public framing of an illness sets initial expectations of illness narrative for a patient at diagnosis. The public frame is all a patient knows upon diagnosis, and is thus, the start of the patient framing "process". As patients live on with

their diagnosis, they experience what it is and means to live with their illness, all the while, evolving their conceptualization of the illness. This evolving conceptualization is multidimensional. There exist parts of the conceptualization that patients keep to themselves, some of which are verbally communicable, others that are not. Then, there are the parts they present to others. Why are the verbally communicable parts not shared with others? And what is shared or presented in their place? The answers to these questions might vary by illness. In any case, answers start at understanding the public framing of an illness, as it is the inception of illness conceptualization for patients. Next, I will evaluate the public framing of breast cancer, and how this might affect patient framing and illness conceptualization.

Public Framing of Breast Cancer

Medicalization begins the process of the public framing of an illness. As mentioned, medicalization and assumption of the "sick role" happens upon a condition being perceived as a threat to social conformity, the biggest of threats being death. Cancer is an example of such a medicalized condition that has historically been associated with death. This association is due to actual mortality counts, but further to historic iteration of cancer as a metaphor for death. In *Illness as Metaphor*, Susan Sontag (2001) reviews the historic usage of cancer as a metaphor for death, war, violence, and colonization. Wilhelm Reich's, a writer influential in crafting societal understanding of cancer, summarizes part of Sontag's explanation. He says, "if my view on cancer is correct, you just give up, you resign, and, then, you shrink,"(Reich, 1987) defining cancer as a hopeless resignation. Countless politicians and political groups—Hitler, Trotsky, John Dean, and more— described their goals of either genocide or excising some corruption as

the elimination of some "cancer". People sick with cancer are rarely ever helped with these violent associations, and are often left feeling ashamed because of them.

Medical descriptions used to discuss cancer are themselves often drawn from the language of warfare. Malignant tumors are "invasive". Micrometastases are assumed outposts of an original tumor that have "colonized" the rest of the body. Immunocompromised individuals' bodily "defenses" are not strong enough, so chemotherapy "kills" both cancerous and healthy cells (casualties), and radiotherapy "bombards" the body with toxic rays. Cancer's historic associations with death and war have positioned cancer patients as victims. Being such a popular metaphor in death and war, it is not surprising that cancer has been a focal point of political advocacy. In health social movements, advocacy groups frame an illness in such a way that necessitates public support for raising resources and awareness that will help ill people. With this motivational dimension, an illness publically becomes more than just the biological condition that has been medicalized. It becomes, in addition, whatever frames the advocacy group might use to achieve their goals.

Health Social Movements and Breast Cancer Advocacy

Brown and colleagues (Brown et al., 2004) apply social movement theory to social movements organized around health-related issues. According to their paper, health social movements' challenge political power, professional authority, and personal and collective identity. It outlines four approaches to social movements: 1) resource mobilization, 2) political opportunity model, 3) cultural framing, and 4) new social movement theory. The cultural framing approach is most relevant to the breast cancer epidemic, as is evident in the widespread pink ribbon campaigns, cancer walks, and fundraising campaigns. During the years of 1991-1993,

breast cancer research federal funding increased from $89 million to $430 million (Kolker, 2004). Kolker (2004) outlines three main cultural frames that activists used during this time to define breast cancer as a public problem to advance funding efforts in congress. It is worth noting that none of these cultural frames are based on nuanced holistic experiences of patients, and are instead founded on social moral responsibility.

The first of these frames is breast cancer as an epidemic, imploring immediate governmental aid. Dr. Love, a prominent breast surgeon and president of the National Breast Cancer Coalition, challenged assumptions about breast cancer being an issue of personal responsibility in congress in 1993. "Why is breast cancer incidence increasing in the young and old? Some would have you believe that it is the fault of the woman herself (e.g., delayed pregnancy, too much dietary fat). But what of the societal causes? What about the carcinogens and hormones in the fat?" (Love, 1993). Dr. Love countered neoliberal assumptions about personal responsibility in causing the illness by framing breast cancer as a structural issue based on societal causes.

The second frame, defined by Kolker, was breast cancer as a problem of gender equity—contending that breast cancer was underfunded because it is a women's disease. Gender equity framing is an easily recognizable frame for audiences, having seen the arguments and discourse circulating even before the women's movement. With this frame, breast cancer was affirmed by advocates as a women's disease. Gender framing lends a path to the third frame mentioned by Kolker: breast cancer as a threat to families.

Establishing breast cancer as a threat to families is a pivot on breast cancer as an issue of gender equity. The gender equity frame alone is not as impactful when employed during times of increased political conservatism. Gendering the issue in another way however, can be useful.

Particularly, gendering the illness as a women's illness, and drawing on pre-existing definitions of womanhood and woman responsibility in the family unit, appeals to conservative American family values. Family based identities like wives or mothers are thus linked to breast cancer. Kolker mentions several speakers in congress and senate who spoke on their experience of the illness, or on their fears of the illness, framing them as the experience of a mother or wife and its effects on children and husbands. In this framing, motherhood elicits sympathy, and in response, funding.

These cultural frames and our existing understandings and narratives about cancer compose the public conceptualization of breast cancer. As previously mentioned, most of this conceptualization is not based on nuanced patient experience. The advocacy cultural frames were based in morality, while the death, bodily decay, and war associations might be attributed to our relative lack of knowledge about the illness. How then, do patients frame and conceptualize their illness as they actively live the nuanced experience the public lacks?

Patient Framing

Two large parts of living with an illness are learning about your illness and finding support while experiencing symptoms and often physically intensive treatments. A client typically learns of their illness on their own, and this knowledge of one's medical state is validated by a formal diagnosis given by a doctor. The patient proceeds to learn about and understand their illness as an individual. Further, the patient can seek out support beyond informational support for their illness. Both of these experiences can shape one's understanding of their illness, and thus their illness narrative.

Learning and Understanding One's Illness

Where do patients gain information and knowledge about their illness, and how effectively do they sift through this information? The answer partially lies in the individual's health literacy. Health literacy (HL) is defined as the "degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions" (Berkman et al., 2010). People with limited general literacy skills have less knowledge about "disease management and health promoting behaviors, report poorer health status, and are less likely to use preventative services than those with average or above average literacy" (Medicine, 2004). Studies have found that women with breast cancer with lower HL levels have less breast cancer knowledge, less perceived severity, and perform breast self-exams less than those who have higher HL scores (Rakhshkhorshid et al., 2018). All these findings suggest that HL levels have an actual impact on patient behaviors and experiences.

Seeking Support

As patients seek knowledge about their illness, they are often offered emotional support both clinically and within their communities. Emotional support systems can play an integral role in illness narrative. It has been found that social support can offset or moderate the impact of stress caused by breast cancer diagnoses (Kim et al., 2010). Further, for breast cancer patients, social support can positively affect their lives (Bozo et al., 2009), and improves their emotional well-being (Dunkel-Schetter, 1984; Holland & Holahan, 2003). All of these positive effects can result in better clinical outcomes (Bortolato et al., 2017; Papanastasiou et al., 2019; Reis et al., 2020). These effects in addition to the information and understanding patients gain about their illness impact their illness experience, and thus impact how they contribute to framing their

illness. We have seen how the processes of framing and patient experience progress, but both processes have been disrupted and changed by the COVID-19 pandemic. And though we have seen examples of how breast cancer has historically been conceptualized, we do not yet know how breast cancer patients are experiencing their illness, and thus collectively framing breast cancer and illness experience in the context of the pandemic.

COVID-19 Pandemic Health Disruptions

COVID-19: Public Interventions & New Social Guidelines

The emergence of the COVID-19 virus, colloquially called coronavirus, was first reported in Wuhan, China in December of 2019 (Qin & Hernández, 2021), and killed its first victim on January 11th of 2020 (Qin & Hernández, 2020). What followed in the next nine days was a rapid global spread of the virus (World Health Organization, 2020). COVID-19 began as an external threat, but soon ran its course to be the cause of the establishment of a new social order around the world. This social order consists of several measures taken for public safety by individuals, corporations, governmental organizations, and other social groupings against the spread and infection of the coronavirus. An initial local public safety measure included advising against gathering in large groups, specifically groups of 50 or more (New York Times, 2020). Corporate businesses began requiring face masks (Josephs, 2020), after the Center for Disease and Control (CDC) released mask wearing guidelines (CDC, 2022), enforcing public-health guidelines within the parameters of their businesses. Airlines were the first to do so (Josephs, 2020), likely as they were the first struck by the impacts of the public safety measures taken to restrict travel. And as the spread of the virus rapidly increased, so did unemployment rates, causing 5 million Americans to lose their health insurance (Banthin et al., 2020) .

How did the virus impact unemployment rates so significantly? Drastic measures were necessary to contain infection, and many countries instituted lockdowns (Hebbar, 2020; Johnson, 2020.; Marey, 2020), requiring or advising people to stay indoors and host all meetings and gatherings remotely. Some schools, health clinics, and other businesses quickly shut down completely, leaving millions without work. Others shifted to remote settings as much as possible, following the CDC's guidelines. All these changes severely disrupted the lives of everyone, including vulnerable patients, who were extra cautioned to "quarantine".

Health Concerns Over Quarantine

How well was the general public able to maintain healthful and fulfilling lives while quarantined? One study found negative psychological effects caused by stressors induced by pandemic social restrictions, including post-traumatic stress symptoms, confusion, and anger (Brooks et al., 2020). The onset of the pandemic especially sparked fear in vulnerable populations that were more at-risk of falling seriously ill if infected. One study found a high prevalence of fear of disease progression among breast cancer patients under the outbreak of the virus (Bandinelli et al., 2021). Why is this high prevalence of fear a matter of concern? COVID-19 related anxiety can affect decision making in breast cancer patients, impacting when patients decide to attend or skip therapy, follow professional medical advice, and more (Vanni et al., 2020). Additionally, qualities of life that are important to breast cancer patient self-care have suffered. Specifically, fear and anxiety surrounding COVID-19 among breast cancer patients has negatively affected sleep quality (Runida & Menekli, 2021). These fears of COVID-19 directly, combined with sharp shifts in daily social life have caused a disruption in normal disease prognosis and treatment progression.

Quarantine orders have further impacted cancer patients as medical offices have reduced the number of clinical appointments, shortened radiotherapy fractionation, converted intravenous to oral systemic therapies, or even reduced or completely halted the frequency of maintenance treatments (Hanna et al., 2020). The stark reduction in treatments might negatively affect prognosis among patients (Kiziltan et al., 2021) . One study from February 2021, in Northern Portugal, found that significantly higher adjusted hazards of death were observed for patients with stage III cancer, and a higher overall short-term mortality rate after the onset of COVID-19 (Morais et al., 2021). Psychological effects of isolating changes in daily social life due to quarantine guidelines have also been seen among patients. Quarantine can cause anxiety, irritability, and depression (Brooks et al., 2020). Previous studies have found that uncertainty increases individuals' emotional distress, and this in turn negatively affects clinical outcomes in cancer patients (Bortolato et al., 2017; Papanastasiou et al., 2019; Reis et al., 2020). Social isolation has also been found to cause feelings of loneliness, which is associated with a higher risk of mortality in cancer patients (D'Ippolito et al., 2017; Hill & Hamm, 2019). These severe potential patient outcomes influence how physicians converse with their patients and instruct them in treatment.

Various studies have shown that the restrictions and isolating nature of quarantine impacted individuals and their daily health. As individuals became less and less physically connected to the world outside their homes, typical health concerns remained. Medical aid became less attainable, as clinics and hospitals reduced taking patients in-person as much as possible, and as individuals hesitated to seek medical help during the insurgence of an infectious and dangerous disease. How large was the effect on medical services provided to patients due to these difficulties? The number of visits to ambulatory practices declined nearly 60% by early

April 2020, and had since rebounded, but was still 1/3 lower than pre-pandemic as of May 2020 (Mehrotra et al., 2020). So, was there an alternative provided to the public to offset the difficulties caused by reduction in in-person accessibility to medical care? Remote care was the most common and significant response.

Remote Care & Healthcare Accessibility

Remote Care alternatives to in-person health care visits were quickly introduced, particularly telehealth visits, either over the phone, messaging, or video call (Fang et al., 2020). There was a 154% increase in telehealth visits during the last week of March 2020 (Koonin, 2020). As in-person visits dropped, telehealth visits increased rapidly before plateauing (Mehrotra et al., 2020). Mobile telehealth users can find messages or reminders about personal health, medical advice, primary diagnoses, prescriptions, and referrals from their mobile device . But how well were these efforts received by actual users? One study reported that, prior to the pandemic, callers found the services provided by one telehealth program to be valuable, but limited in population reach and integration into the wider medical system (Alam et al., 2019) .

Though not very popular among users, remote care has since become the prominent mode of nonurgent and non-therapeutic health care visits (Koonin, 2020). The Global eHealth Market was set to grow 18% over 2021-2026 by Research and Markets (ltd, n.d.). Telehealth operations were further integrated into the medical system after the onset of the pandemic. One study (Badawy & Radovic, 2020) found only eight percent of Americans had previously used telemedicine in 2019, and this percentage significantly increased in 2020 (Badawy et al., 2020). Barriers to wide adoption of remote health care options reported by those surveyed included

discomfort of patients, parents, and providers in using telemedicine technology and overall

preference for in-person visits.

Shifts in the Physician-Patient Relationship Over Quarantine

Unequal and inefficient accessibility to remote care is only one stressor inducing change

in the physician-patient relationship during the pandemic. Historically, the physician-patient

relationship has initiated and proceeded in the material form, not over digital space. And what

has the physician patient relationship been to-date? To establish this relationship theoretically, I

will delineate the relationship between physician and patient as one between an agent and a

principal. An agent-principal relationship (Mayer et al., n.d.) is one built upon duties owed to a

principal fulfilled by an agent. The relevant duties include fiduciary duty, avoid self-dealing,

preserve confidentiality, duty of skill and care. Fiduciary duty is one in which the agent "stands

in a position of special trust" and has a responsibility to "subordinate his self-interest to that of

his principal". Avoiding self-dealing refers to refraining from advising one's principal to a means

that would be beneficial to oneself. Duty of skill and care refers to performing one's work with

the skill and care that is "standard in the locality for the kind of work which he is employed to

perform". A physician or healthcare provider, serving as agent to their principal, the patient,

follows these duties as it is in the best interest of public health and wellbeing. The extent to

which the patient participates in this agent-principal relationship, is a different matter, addressed

by Emanuel's Four Models of the Physician-Patient Relationship.

Emanuel (1992) describes physician-patient relationships taking four models:

paternalistic, informative, interpretive, and deliberative. The paternalistic model describes when

patients receive the medical intervention best for their health and well-being, an intervention

decided fully by the physician. Informative model is one in which the physician provides the patient with all relevant information to their condition and possible interventions to help the patient decide on their own. The interpretive model aims to elucidate the patient's values and desired outcomes to help the patient select the best interventions to realize these values. The deliberative model aims to help the patient determine and select the best mode of action, often dismissing "elements of morality" deemed important in the deliberative model, as irrelevant to the patient's condition. Each of these models describes a different extent to which the patient participates in their healthcare decision making. These four models in hand with the agent-principal duties makeup theoretically what is the social relationship between patient and care provider. But why does evaluating the preexisting relationship between physician and patient matter? The relationship has evolved over history. Kaba and Sooriakumaran (Kaba & Sooriakumaran, 2007) state the relationship has shifted through the ages, from a more paternalistic model to a more patient-centered role, as critics advocated for active patient participation in healthcare decision-making. Whenever this dynamic has shifted, whether in era, location, and/or human condition, it has always evolved in the material form until the pandemic, where much of the shift has occurred digitally. The effects of this digital shift on the relationship, and on health outcomes are yet to be thoroughly and clearly evaluated.

Patient Social Changes in the Shift to Remote Care

A shift to the digital space has eased many patients' and providers' fears of COVID-19 infection and has even made doctors' visits more accessible to some. But what of the implications this shift has had on the physician-patient relationship, and on other patient social relations? I consider patient social relations by demarcating a "patient" as a person in the context

of medicality, distinguishable from a "person with an illness" outside the context of all medicality. Thus, patient social relations are distinctly those that a person with an illness has in the context of their experience with the illness, not necessarily the dynamics that may also constitute a nonpatient's social life. The shift to remote care has resulted in two distinguishable social outcomes for patients, particularly those who are normally frequent visitors of hospitals and health centers. Firstly, patients have less in-person interaction with physicians, and secondly, patients less frequently encounter and interact with fellow patients in person.

The first result has been well studied relative to the second. Reeves and colleagues (Reeves et al., 2021) study the downsides of fewer in-person visits, focusing on the flaws of telehealth. They list incomplete or inaccurate physical examinations, inadequate patient-home environment or space, poor lighting, discoloration with resultant poor visualization, increased time required for assessment, and other technical issues. These flaws result in the harmful inability of a physician or nurse to efficiently follow regular aspects of physical examinations, such as auscultation, assessing heart and lung sounds, measuring blood pressure, and more. Another study found that some patients perceived virtual examinations as inadequate, and another study found that 80% of US patients will "always prefer in-person visits to telehealth after COVID-19"(Laday, 2021). Though telehealth was a cost-effective replacement for in-person care and effectively slowed the spread of COVID-19 (CDC, 2020), it is yet to be known the implications the shift had on the physician patient relationship.

The second result, that patients less frequently encounter and interact with fellow patients is one well worth studying. Though, not much research has yet been published on the effects of this change. Reduction in interaction among patients is due not solely to the shift to remote care, but also to social distancing guidelines at in-person care centers, as well as lost

nurse facilitation of peer connections. This is a twofold pressure on social interactions among peer patients: visiting care centers less, and not interacting even while at care centers. Why is studying the effects of this relative isolation important? Previous studies and cancer center journalism have found the importance and value in social interactions with fellow peers while undergoing health therapies. Cancer journalist Bethany Kandel records testimonies (Kandel, 2019) from nurses at a cancer center. One nurse witnessed patients often becoming friendly during their therapy chair visits, sometimes on their own, and sometimes with the help of a nurse. This support between peers is especially important when family and friends cannot be there, particularly important through the pandemic, where many cancer centers restricted visitation policies (American Cancer Society, n.d.), forcing cancer patients to attend therapies alone (St. Francis - Emory Healthcare, 2020.; UPMC, 2020; USCF Health, 2020.; Yale Cancer Center, 2020).

This reduction in social interaction disrupts patients' illness narratives as they are of value. How do patients value these interactions? An interview (Renberger, n.d.)found that multiple cancer patients witnessed their patient peers have great experiences becoming friends with others in the chemo room. They claimed these were particularly important as people could get support from others who have a common goal, a shared experience, and can have fun through a condition that is depriving them of many normal experiences. Some cancer centers even actively promote making friends in the chemo room with brochures and encouragement on their websites (Scott, 2018). Not only is the interaction between two peers a form of human connection, but these peer relationships also often take the form of mentorship and support. There are some programs that institute peer support through cancer centers, many of which

receive positive feedback from cancer patient participants (Ashbury et al., 1998; Jefferson

Regional, n.d.; Renberger, n.d.).

Not to mention, patients have also lost key sources of information with these restrictions.

Testimonies from breast cancer patients show that sharing stories and information about illness

experience is a valuable part of a shared chemo room experience (CancerConnect, n.d.; McCain,

2021; Renberger, n.d.; Scott, 2018). Unfortunately, the pandemic has seen cancer patients

attending chemotherapy in relative isolation. Studying how these changes are impacting patients

is particularly important as remote care becomes a new norm even beyond the pandemic. If we

have seen that social interaction for patients undergoing medical treatments has historically been

of value, it is important to understand how else patients are finding information, community, and

support, and if these forms of sociality and connection are sustainable and effective at meeting

the needs of vulnerable populations.

With the loss of many of the material sources of support, both informational and

emotional, many patients are turning more to online information sources (CDC, 2022b), and

social media for emotional support (Moraliyage et al., 2021). The effects of this shift in medium

of support over the pandemic for patients is currently, relatively understudied. What we do know

is that fears surrounding coronavirus are more pronounced among patients who used social

media more often (Ugas et al., 2021). Less than 50% of patients feel satisfied with online health

information, and those with chronic diseases are significantly less satisfied (Ugas et al., 2021).

But what are the problems most concerning breast cancer patients at this time? What are the

strategies and improvisations through which they are attempting to deal with and make sense of

these problems in the new circumstances? How are the new prominent online spaces for patient

conversation evolving and shaping? It is vital to prompt these discussions to understand how

breast cancer patients are collectively crafting and framing their illness narratives in the pandemic. In the next section, I turn to my methods on gleaning how breast cancer patients search for and find community within online patient forums and frame their experiences during the COVID-19 pandemic.

METHODOLOGY

Data:

Online Patient Discussion Forums

Data was collected from two separate organizations who host online breast cancer patient discussion forums. The data collected are forum comments and posts made from January 2020 through February 2022. Since the data came from two separate online forums, one based in the United Kingdom, and the other based in the United States, it is assumed most of the data is sourced from these two countries, though, because of the accessibility through the internet, it is possible there are data sourced from elsewhere as well. The population from which the data have been gathered are mostly current or recovering English-speaking breast cancer patients, and possibly loved ones of such patients who have been affected by breast cancer, who have access to the internet. This population was selected because from online forums, we can begin to answer questions about how breast cancer patients are seeking and creating community among one another during quarantine and isolation through the COVID-19 pandemic. The dataset consists of 9015 comments. The lengths of subsets of data for specific analyses are presented in the table below.

Subset	Medical Advice (Both Forums)	Social Subset (Both Forums)	COVID-19 Subset (Both Forums)	Overcoming Illness (Both Forums)	Medical Advice (Forum 1)	Social Subset (Forum 1)	Medical Advice (Forum 2)	Social Subset (Forum 2)
Length of Data	2821	1757	718	686	540	208	2145	1549

The data were collected by scraping threads from two different breast cancer patient forums, whose names will be left out for privacy reasons. The first forum is a subgroup, part of a larger American medical forum site that hosts forums for specific illnesses like breast cancer. This breast cancer subgroup has around 1624 members, with over three hundred thousand posts. The second forum is hosted on a British website hosted entirely for the purpose of breast cancer, and has over 1.2 million posts, and seventy one thousand users, of which 300 are active. Threads from both include a main post that defines the topic for a thread, and comments by users that form a discussion surrounding that topic. These two forums were selected as each provides an online platform for breast cancer patients (and loved ones) to discuss problems pertinent to my chosen research illness, breast cancer. Additionally, both forums are popular and reputable relative to other online breast cancer forums, are advertised by leading breast cancer associations, and have privacy permissions that allow such data collection.

Online discussion forums are the obvious alternative to in-person community during quarantine in a digital age. They provide a relatively private democratic platform that anyone

with internet access can access. With such high access, it is likely much more representative of a broader population than institutional sources of data that may privilege the experiences of those with higher access to better care (*Internet Discussion Forums, an Information and Support Resource for Orthognathic Patients - ClinicalKey*, n.d.; Tighe et al., 2017). Further, online forums, unlike interviews and surveys, are a nonreactive form of gathering information on a community in an observatory manner without prompting common subject related biases (*Parkinson's Disease: Content Analysis of Patient Online Discussion Forums. A Prospective Observational Study Using Netnography - ClinicalKey*, n.d.; Vaughan Sarrazin et al., 2014). These forums are thus an excellent focal point to evaluate how breast cancer patients are collectively crafting illness narratives during quarantine.

Data Collection

The scraping script searched up several keywords and pulled all the comments from every thread that came up under the search. Selected search terms were *coronavirus, covid, covid-19, mask, pandemic, telehealth, quarantine, zoom*, and *isolation*. These words were selected from the WebMD Coronavirus Glossary of Common Terms (Brody, n.d.). Words were selected according to colloquial relevance, as we expect patients to speak in colloquial terms in casual online forum settings. Care was taken not to select words that may elicit cancer-related comments that are not necessarily related to coronavirus. Using these search terms alone was all that was needed in the search query as both forums were already solely for breast cancer patients, so no extra indicator for breast cancer was needed.

These data were scraped on a grace cluster computer using the BeautifulSoup and Requests python packages. The comments and posts that were pulled were immediately

anonymized, with each user assigned a unique ID, though all the data is publicly available online. The variables collected included the comment or post body, the post each comment is associated with, number of likes each comment received, and the date the comment/post was made, in addition to the anonymized user id created with the usernames.

Analysis Methodology

Natural language processing (NLP) can be defined as computational textual analysis methods (Lucy et al., 2020) built upon mathematical linguistic models. Social sciences are increasingly finding great use of this technology (Grimmer & Stewart, 2013; Nguyen et al., 2020), along with social healthcare research (Chew & Eysenbach, 2010; Mamidi et al., 2019; Saleh et al., 2021; Taylor & Pagliari, 2018). Natural language processing holds the capacity to somewhat reduce human bias in analysis, providing an exactly repeatable standard set of procedures to extract information and common themes in large bodies of text relatively quickly. With these advantages, NLP serves as a great methodology to analyze large amounts of text, like text provided in the forum data in this study, in shorter amounts of time, in a repeatable fashion.

Though various social healthcare studies have made use of NLP to extract valuable information about patient experiences and perceptions for these advantages, it is important to understand that NLP best serves as a complement, and not a replacement, to more holistic analyses like ethnographies and case studies (Lucy et al., 2020, p. 202).

Preprocessing

When conducting analyses on text data, the data must first be cleaned and prepared for more complicated algorithms to work effectively. This includes pulling the text data from the dataset, removing any non-vernacular content, and finally lemmatizing and stemming all the text.

After the text data is pulled from each of the three data set as "documents", we can use the gensim and nltk python libraries for lemmatizing and stemming the words. While searching for themes in the documents, individual words must be shortened to their stem. This is so that words having the same contextual meaning, but differing tenses, can be assigned the same "definitions" in our model. Stemming itself takes words and pulls the pseudo "stem" of each word, ignoring contextual meanings of words. With just stemming, words such as care and car would both be stemmed to "car", which would be erroneous (*Nlp - What Is the Difference between Lemmatization vs Stemming?*, n.d.). Lemmatizing words before stemming can fix this issue, as lemmatization uses context to find the correct definition for a given word to find its real stem. Once all the words in documents have been lemmatized and stemmed, we can begin the process of vectorizing the words, or in other words, creating mathematical formulations of the text we can use for analysis.

Word Embeddings and Vectorization

To move forth with topic modeling, the corpus data must be transformed into word embeddings, or numerical vectorized forms of the documents. Two common methods for word embeddings are bag of words (BoW), and term frequency-inverse document frequency (tf-idf). I first create a vocabulary, pulling all unique words from the corpus. BoW takes the documents, and creates a document-term matrix, marking which documents contain each given word in the corpus vocabulary with 1, and words a document does not contain with 0. One of the problems with BoW is that because there are so many words that will not show up in most documents, many entries will be 0, meaning there is high sparsity, which can be computationally expensive

to work with. A better option, which results in less sparsity, as well as generally better outcomes

in topic modeling, is tf-idf (2020), the embedding method that is used in this project.

Tf-idf involves two parts: term frequency, and inverse document frequency. Term

frequency for each term in the vocabulary is calculated for each document as the number of

times the term appears in a document divided by the number of terms total in that document.

$$tf_{t,d} = \frac{n_{t,d}}{Number\ of\ terms\ in\ the\ document}$$

Inverse document frequency is calculated per word by calculating the log of the division of the

number of documents total by the number of documents containing the word.

$$idf_{t,d} = log\frac{number\ of\ documents}{number\ of\ documents\ with\ term\ 't'}$$

The tf-idf document-term matrix entries are calculated by multiplying the above two terms:

$$tf\_idf_{t,d} = tf_{t,d} * idf_t$$

Model Building

To glean topics within each subgroup, latent Dirichlet allocation is used as it is the most

common and effective generative probabilistic model used for topic modeling in machine

learning. First, each word in each document is randomly initialized to a topic among K topics,

where K is a predefined number of topics to glean. For each document d, the proportion of words

in document d that are assigned to topic t is calculated, $P(document\ d)$.

Then, the proportion of assignments to topic t across all documents from words that come

from w is calculated, $P(topic\ t)$. Using these calculations, topic T is reassigned to a word w

with probability $p(d) * p(w|t')$ considering all other words and their assignments. This is

repeated multiple times, or passes, until topic assignments do not need further change, and the

proportion of topics for each document is then determined from these topic assignments. Latent Dirichlet allocation inputs can be word embeddings in either BoW form, or tf-idf form. For this project, after testing both forms, tf-idf was found to produce more interpretable results for topic modeling (*Topic Modelling With LDA -A Hands-on Introduction - Analytics Vidhya*, n.d.). All preprocessing and algorithmic processes were conducted using popular python libraries including nltk, gensim, and pandas.

I will tune the topic model parameters to pull the model, per question, with the highest coherence scores. This is determined by running models with varying values for the number of topics, calculating the coherence score for each, and finalizing the model with the highest score. The topic model yields a distribution of common words in that model, and with pandas and the pyldavis packages in python, each topic can be visualized and explored to interpret and finally be labeled.

Four topic models were created on subsets of the entire dataset, operationalizing each subset on one of the four following realms.

1. **Medicality:** Sought out and given medical advice
2. **Emotionality:** South out and given social/communal emotional support
3. **Healing:** Conceptual approaches to overcoming breast cancer
4. **Pandemic Times:** COVID-19 conditions

Further, each of the first two realms were pulled on each forum separately to pull more specific topics found in each forum, making for eight topic models total.

RESULTS

Below are the found topic models per four realms mentioned: Medicality, Emotionality, Pandemic Times, and Healing. The word distribution associated with each realm and topic can be found in the appendix. I present the relevant topic models and proceed to analyze them in context of example comments as well as literature in the subsection following.

Topic Models

1. **Medicality:** Sought out and given medical advice
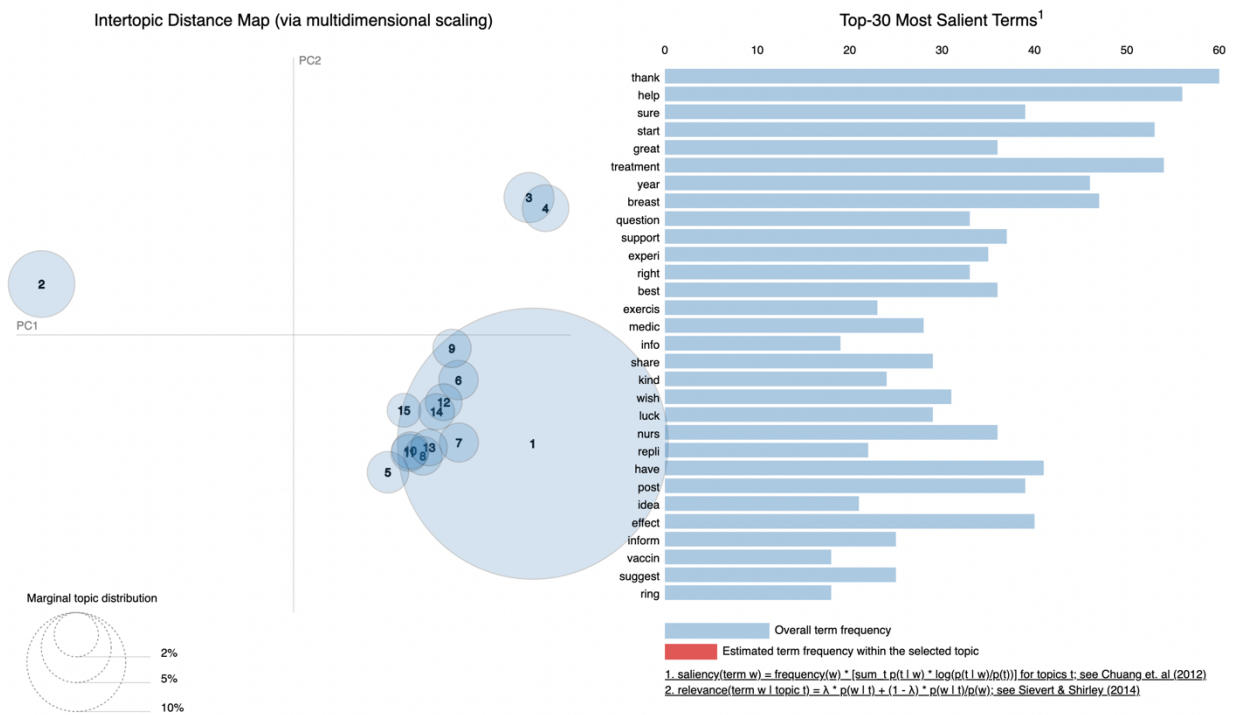
Topic 1: Daily Health & Settling into "Daily Life"

Topic 2: Beauty

Topic 3: Specific Remedies (At home or Over the Counter)

Topic 4: Sharing external sources / *Talking about* sharing own experiences

Topic 5: At-Home Exercise / Bodily Beauty, Strength, & Ease

Topic 6: Menopausal experiences while going through BC (Explicitly connecting back to discussions more common on Facebook groups *can maybe find literature on this part..middle aged women on fb etc.*)

Topic 7: Everything About Health While Online (problems with sitting still all day, telehealth visits, connecting with one another via zoom)

Topic 8: Inflammation: Skin, mouth, face conditions

Topic 9: Breast Reconstruction (Sharing entire treatment course) / COVID Vaccinations

Topic 10: Joint pain advice and advice success

Topic 11: Dealing with Common Illnesses (Cold, etc.)/ Advice on how to approach medical situations (talking to doctors, thinking through medical decisions, etc.)

Topic 12: General Expressions of Gratitude for Sharing/Helping

Topic 13: Planning for Medical Visits (specifically for scans/tests/etc.)

Topic 14: Throwaway Topic

Topic 15: Anxiety and Coping with Mental Pathology
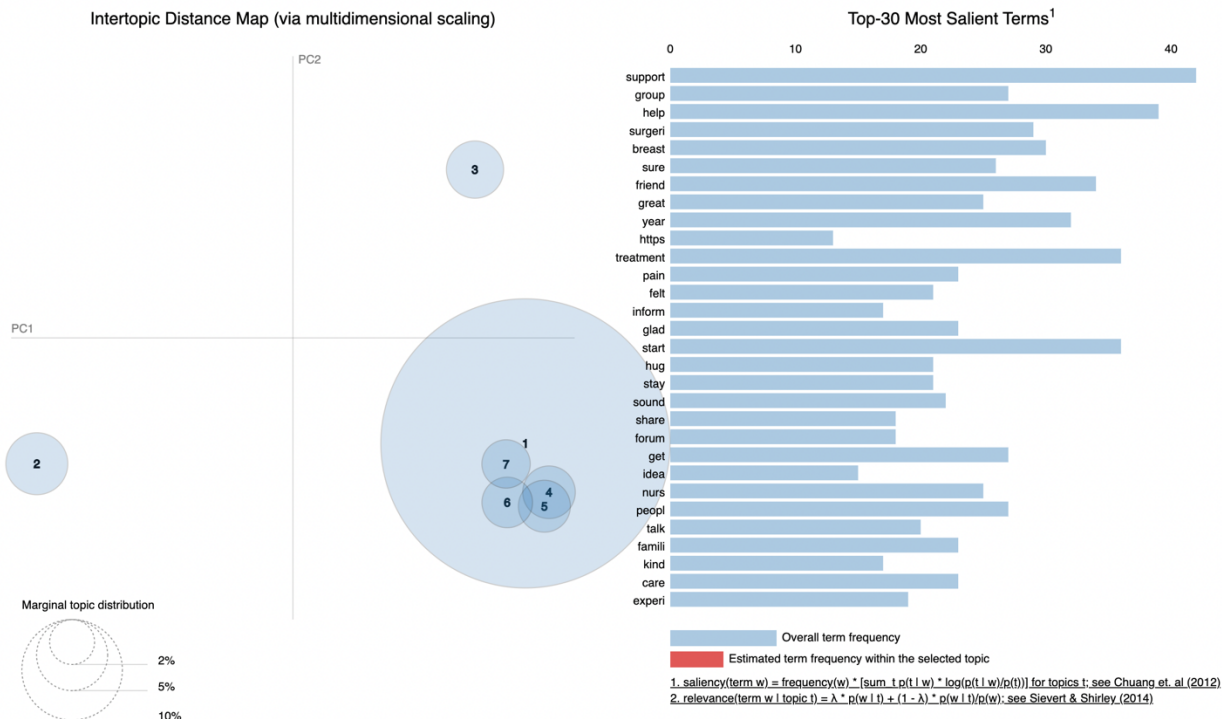
Supplemental Topics Observed:

1. Changed conceptions of "health" (HIGHLY MARKED IN TOPIC 4)

2. Medical professionals as patients

This topic model yielded several expected topics of conversation relevant to medical advice and discussion. Topic 1 covers daily health conversations, and conversations about settling into "daily life" as a breast cancer patient undergoing therapy. Topics 2 and 5 cover conversations

regarding physical appearances, in general beauty, and in bodily beauty and strength. Topics 3, 4, and 15 cover conversations providing remedies, resources, and coping advice, and topic 12 covers comments expressing gratitude to others for sharing advice, stories, and experiences on the forum. Topics 6, 8 through 11, and 15 cover comments on more specific medical issues and medical procedures, including mental pathology. Topic 7 covers everything pertaining to health while in an online world during COVID, including problems with being still all day, telehealth visits, and connecting with one another via zoom. Topic 13 covers comments related to planning for medical visits, specifically for scans and tests.

Supplemental topics beyond factual mentions of certain medications, treatments, and conditions included changing conceptions of what "health" is, and medical professionals as patients. The former was highly marked in topic 4: Talking about sharing stories and experiences. This is a notable finding as it indicates some consciousness of how sharing experiences in such a group setting may influence conceptions of what "health" is and looks like as a breast cancer patient during the COVID-19 pandemic.

2. **Emotionality:** South out and given social/communal emotional support

Intertopic Distance Map (via multidimensional scaling)

Top-30 Most Salient Terms[1]

1. saliency(term w) = frequency(w) * [sum_t p(t | w) * log(p(t | w)/p(t))] for topics t; see Chuang et. al (2012)
2. relevance(term w | topic t) = λ * p(w | t) + (1 - λ) * p(w | t)/p(w); see Sievert & Shirley (2014)

Topic 1: Advice on Getting by Day to Day

Topic 2: Active group building (introductions, encouraging connections, etc.)

Topic 3: Seeking/Finding "On-Call" Support/ How to live a smooth life (easing logistical tensions to reduce stress)

Topic 4: Explicit Bonding and Relationship Building within Group

Topic 5: Inquiring about one another (wellbeing, personal life, etc.)

Topic 6: Living Life Regardless of Diagnosis (Travel, Nature, etc.)

Topic 7: Celebration and Holidays Discussions/ Being Strong for Loved Ones
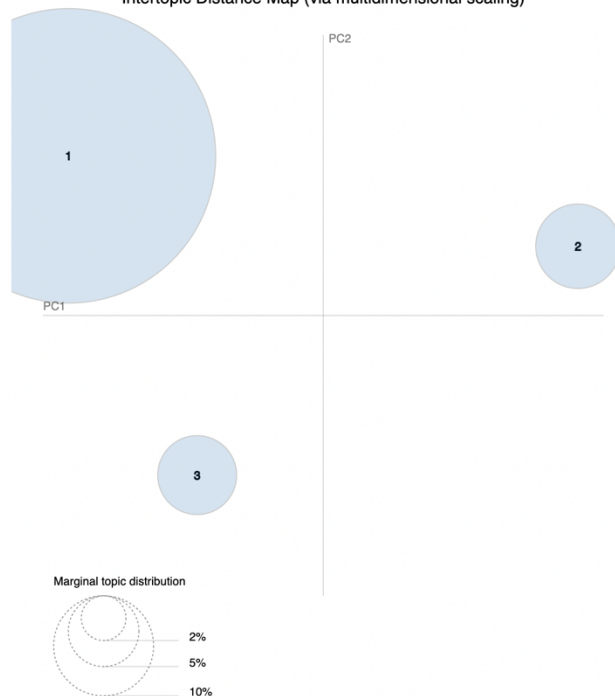
Supplemental Topics Observed:

1. Emotionality generally

2. Handling external Relationships (Daughters, Mothers with Cancer, etc.)

3. Advice on Hospice Support

This social or "communal" topic model similarly yielded quite expected comments providing non-medical support and advice, as well as explicit discussions about connection building and providing non-medical support. Topics 1, 6, and 7 cover comments generally providing non-medical advice about more mundane occurrences like holidays, and day to day events. Topic 3 covers comments providing emotional support in the form of external resources like "on-call" support and advice on how to reduce logistical stressors. Topics 2 and 4 cover active and explicit group bonding conversations, including introductions, encouraging connections, and establishing a safe space for vulnerability. Topic 5 covers examples and outcomes of these active efforts to build group cohesion in the form of inquiries about one another's personal lives and wellbeing.
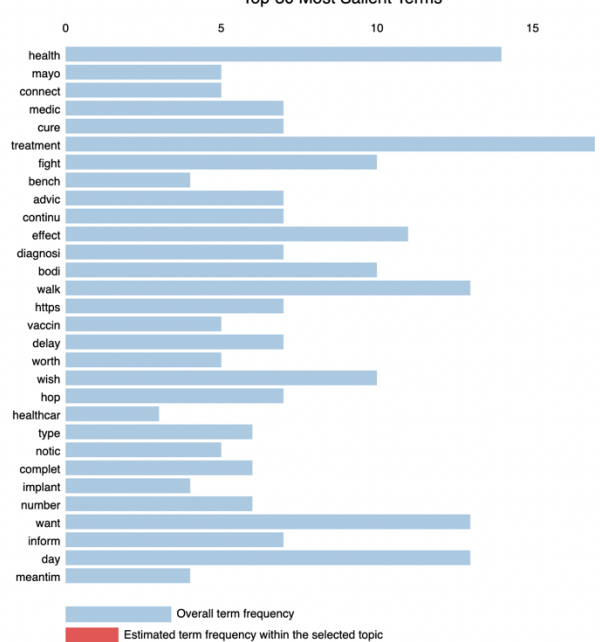
Observed supplemental topics cover comments about handling and coping with emotional experiences outside the group, being additional examples of the efforts. The topics include internal emotional states, relationships, and advice on the emotionally loaded endeavor of seeking end-of-life care.

3. **Healing:** Conceptual approaches to overcoming breast cancer

Intertopic Distance Map (via multidimensional scaling)

Top-30 Most Salient Terms[1]

Marginal topic distribution

Overall term frequency

Estimated term frequency within the selected topic

1. saliency(term w) = frequency(w) * [sum_t p(t | w) * log(p(t | w)/p(t))] for topics t; see Chuang et. al (2012)
2. relevance(term w | topic t) = λ * p(w | t) + (1 - λ) * p(w | t)/p(w); see Sievert & Shirley (2014)

Topic 1: Healthy Living with Treatment Coupled with Time

Topic 2: Accepting One's Diagnosis and Following Advice

Topic 3: Being Brave (Less frequent: Anger, Fighting)

    This topic model yielded the three most common paradigms when approaching overcoming

breast cancer. The first is developed upon general healthy living through treatment, coupled with

time and patience. In other words, one waits out their time with the condition and treatment

course while positioned in a healthy lifestyle. The second focuses on acceptance, and with

acceptance, surrendering to, and following doctor and peer-given advice. The third, and least

common approach to healing focuses on being brave, which can involve validating or honoring

one's anger, sometimes by "fighting" its catalyst, the illness.

4. **Pandemic Times:** COVID-19 conditions
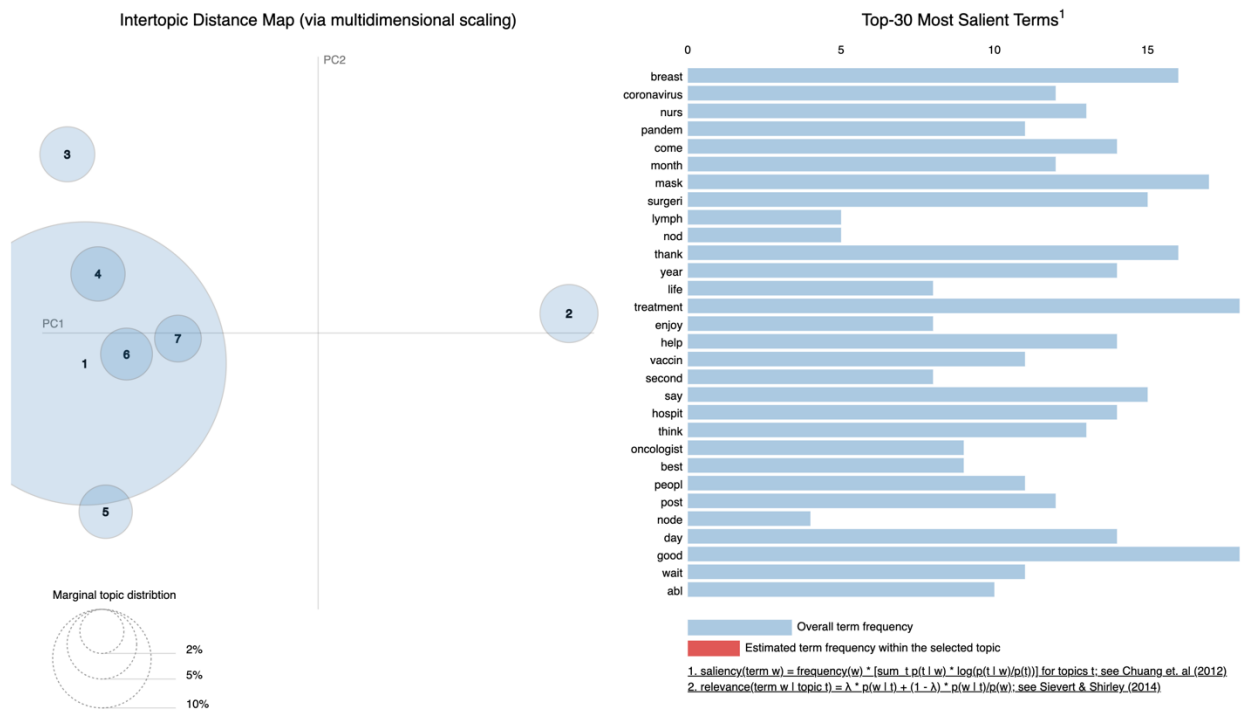
Topic 1: Public Spaces/ Others in COVID (Comparing COVID for everyone as having

Cancer: everyone taking same precautions and doing same things as cancer patients now)

Topic 2: Oncological Psychology for Isolation

Topic 3: Fear of COVID, Coping with COVID Conditions (isolation, fear, etc.)

Topic 4: Waiting, Postponements of Medical Procedures

Topic 5: COVID forcing people to do own research

Topic 6: Breast Cancer Treatment After Being Affected by COVID

Topic 7: Actively Ignoring/Missing Medical Appointments

Supplemental Topics Observed:

1. Masks during therapy / Other COVID public safety measures during medical procedures

This topic model pulls topics of conversation from a subset of the data that isolates explicit mentions of covid conditions. Topic 1 consisted of two subtopics, both pertinent to the public experience of COVID. Specifically, it covered comments about being in public spaces, and comparing the public experience of the pandemic to the individual experience of having breast cancer outside of a pandemic. Topics 2 and 3 cover comments regarding psychological impacts of the pandemic, including isolation due to pandemic conditions, and fear of being infected. Topics 4, 6, and 7 cover comments about how COVID-19 has impacted and/or delayed their treatment and medical procedures. Topic 5 covers discussions about an interesting, allegedly positive, outcome of the pandemic: an increased focus on and desire for health literacy. Supplemental topics observed were about public safety measures, and how these measures apply during medical therapies and procedures.

5. **Forum 1. Medicality:** Sought out and given medical advice

Intertopic Distance Map (via multidimensional scaling)

Top-30 Most Salient Terms[1]
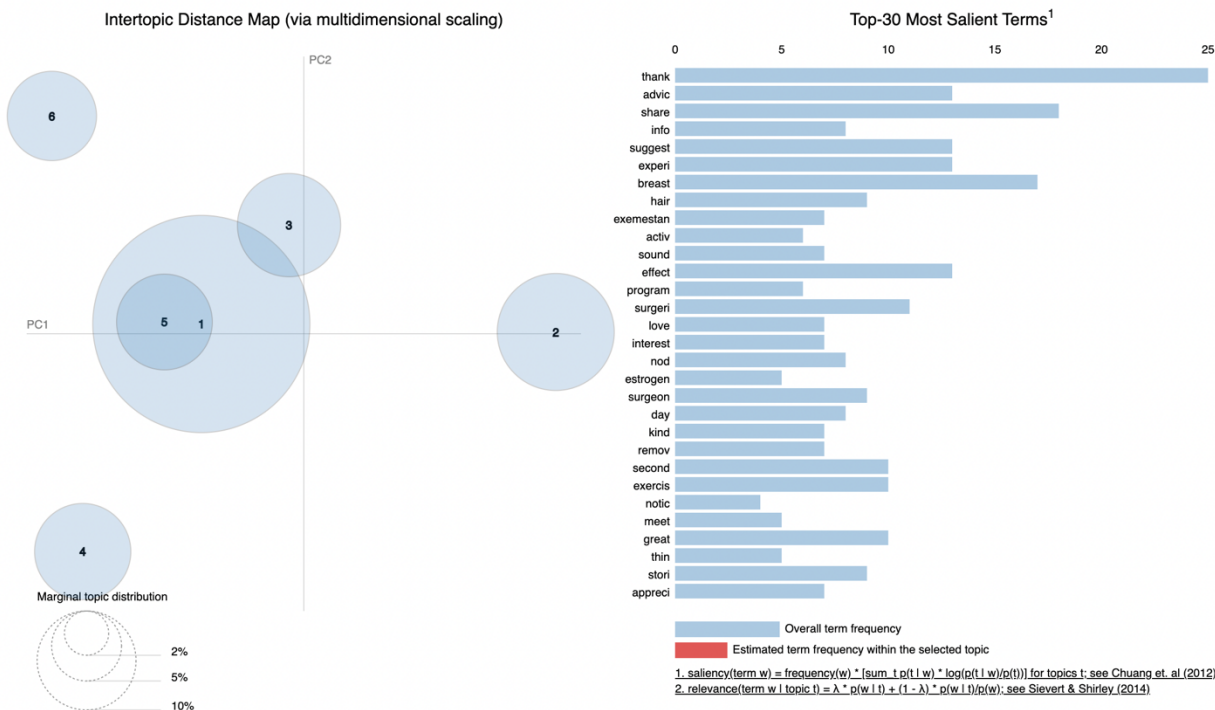
Topic 1: Length and Time of treatment

Topic 2: Inquiring about Medical Procedures (surgeries, biopsies, radiation, etc.)

Topic 3: Process of getting Doctor's Advice

Topic 4: Sharing Stories for specific advice

Topic 5: Scans/Testing

Topic 6: Reflecting on Positive Sociality

Topics 2, 4, and 5 pertain to discussions about medical advice, including comments about procedures, diagnoses, and scans or testing. Topic 1 covers comments about the length and times of treatments, both generally, and during the pandemic. Topic 3 covers discussions surrounding the process of getting a doctor's advice. The final and least prevalent, topic 6 covers comments where patients reflect on positive social interactions within the group, indicating some satisfaction with the medical advice received through the forum.

6. **Forum 2. Medicality:** Sought out and given medical advice
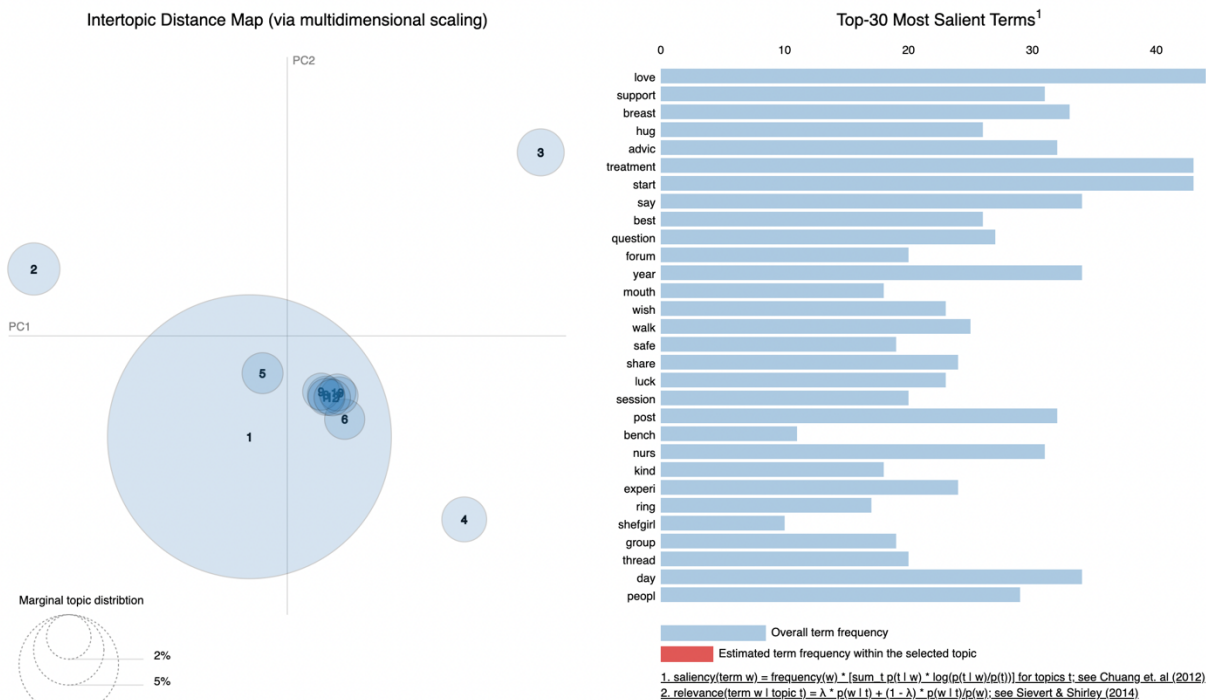
Topic 1: Treatment Length/ Timing

*Topic 2: Throwaway Topic

Topic 3: Cooking/Home Keeping

Topic 4: Medication Side Effects

Topic 5: Zoom Conversations/Online Emotional Support resources

Topic 6: Allergies and Seasonal Cold/Flu Advice

Topic 7: Financial Conversations

Topic 8: Gift Giving/Special Occasions

Topic 9: Missing Pre-Cancer Things (Alcohol, Beauty things)

Topic 10: Handling Time off Work

Topic 11: Pain from Treatment and Medications

Topic 12: GI and Oral Cavity Issues

Topic 2 pulled mutable strings with irrelevant internet protocol language hidden in the data

Topics 4, 6, 11, and 12 cover conversations directly related to medical advice, including medication, seasonal illness, physical pain, and more specific gastrointestinal and oral cavity issues. Topic 1 covers conversations about the length and timing of medical treatments and possible delays due to the pandemic. Though this subset of the data is focused on medical advice, the remaining topics are not directly connected to medical advice. This indicates some level of infusion of these topics within a conversation about medical ailments. All these topics exist in the context of conversations about health and are often conversations about these topics pertinent to their illness. Topics 3, 7, and 8 cover more mundane conversations, including cooking, housekeeping, financial matters, and special occasions. Topics 9 and 10 cover comments about changed conditions due to cancer and the pandemic, such as missing pre-cancer habits, like alcohol consumption, beauty related experiences, and handling time away from work. Topic 5 covers comments where individuals discuss personally providing emotional support or providing resources for such support.

7. **Forum 1. Emotionality:** South out and given social/communal emotional support
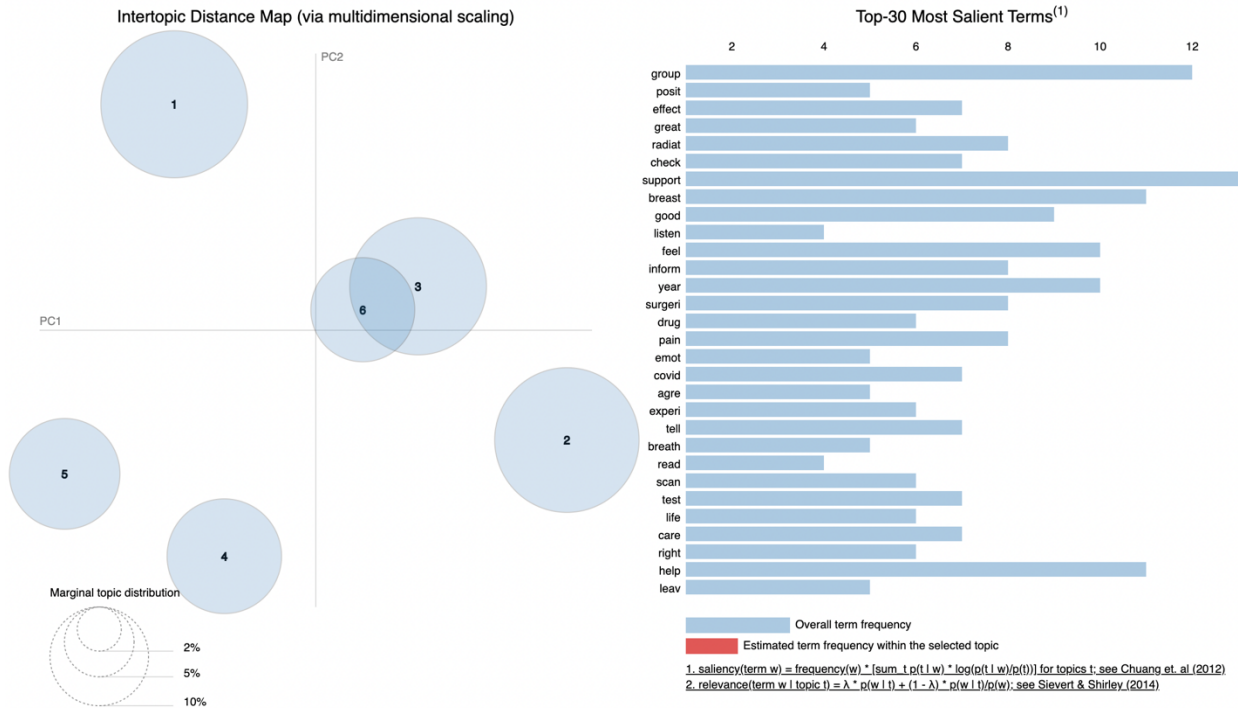
Topic 1: Physical/Surgical Consultations
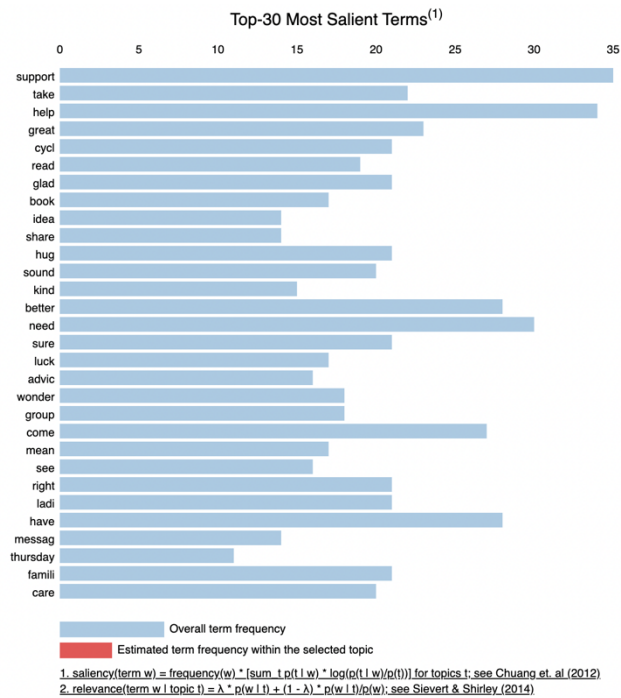
Topic 2: Timeline of Oncology Journey

Topic 3: Family/Friend Medical Advocacy

Topic 4: Mastectomy COVID-19 Concerns

Topic 5: Talking to Doctors

Topic 6: Long Term Drug Effects

8. **Forum 2. Emotionality:** South out and given social/communal emotional support

Intertopic Distance Map (via multidimensional scaling)

Top-30 Most Salient Terms[1]

| | | | | | | | |
|0|5|10|15|20|25|30|35|

support
take
help
great
cycl
read
glad
book
idea
share
hug
sound
kind
better
need
sure
luck
advic
wonder
group
come
mean
see
right
ladi
have
messag
thursday
famili
care

Overall term frequency

Estimated term frequency within the selected topic

1. saliency(term w) = frequency(w) * [sum_t p(t | w) * log(p(t | w)/p(t))] for topics t; see Chuang et. al (2012)
2. relevance(term w | topic t) = λ * p(w | t) + (1 - λ) * p(w | t)/p(w); see Sievert & Shirley (2014)

Marginal topic distribtion

2%

5%

10%

Topic 1: Temporal Treatment Concerns

Topic 2: Quarantine Lifestyle and Children

Topic 3: Bookclub, Things to Do for Fun

Topic 4: Relaxation Activities

Topic 5: Second Opinions

Topic 6: Group Exercise and Group Activities

ANALYSIS

Here, I take the findings and answer the research question: *How were breast cancer patient illness narratives formed during COVID-19?* I present my analyses organized in two broad categories: Illness and Self, and Illness in a Social Context. These two categories fall under the larger umbrella of illness narrative, which has multiple dimensions that fall into two main themes revealed in the forums: roles and relations. Roles include the preoccupations of a person or group, specifically how they interact with and understand the illness itself. Relations include how the illness impacts one's connection with and understanding of realms outside the illness, like one's life, self, and others. I discuss roles and relations within both broad categories, and follow by exploring how they were impacted by the pandemic. Roles and relations are of course not distinct, nor mutually exclusive, and are in fact reciprocally influential, so each section will have mentions of how roles might influence relations, and vice versa.

Illness and Self

In this section, medicine and health encapsulate how patients are able to assume a personal role in their illness narrative, while appearances and narratives cover how patients relate their experience to personal spheres outside the illness.

Roles: Personal Medicine and Health

Medicine

Several topics pulled from the data were specifically disease and treatment oriented, as opposed to support or illness experience. Topics pertained to allergies, daily health, common illnesses, and most notably, to approaching medical situations, including talking to doctors and

making medical decisions. Users adamantly encouraged seeking second and even third opinions

when it came to professional medical advice--whether for diagnosis, prognosis, procedures, or

treatment (see Box 1). In addition to seeking multiple opinions, they confidently expressed to

others the need to advocate for oneself (see Box 2). Actively advocating for oneself became

especially important when doctors were not "listening" to the patient's issues, with one user

claiming that "pretending there is no problem certainly can't be the best plan either". These

comments indicate a desired shift to more active participation in one's medical decisions,

particularly those decisions made against a doctor's direct advice. Comments describing medical

professionals overlooking or neglecting patient concerns were common (see Box 3). One user

had mentioned suspicion of lymphedema to her doctor, who quickly dismissed, or

"pooh-poohed" her concerns. In response, she asked the doctor what they would do if she "didn't

have any arms", to which the doctor shockingly suggested she was "carrying things just a little

too far". Neglected patient concerns go beyond direct medical questions.

1. *"That's no fun at all, is it. I'm guessing that ******** may not offer many choices, but the only advice that I can recommend is that, if for any reason you are not feeling good about any or all of your doctors, do not hesitate to get a second opinion. You will want to feel confident about both your diagnosis and treatment plan. Best of luck to you on this new journey."*
2. *"I managed to get through all treatments without interruption and I'm still here. The one advice I want to give you now is to get a second- and third opinion if necessary. The time to do it is before you start any treatments.It should be with a major cancer dedicated hospital. I do recommend **** ******."*
3. *"You will need to advocate for yourself in this. If your doctor won't listen, I would humbly suggest a second opinion might be in order. Maybe this drug isn't right for you, but pretending there is no problem certainly can't be the best plan for you either."*

Box 1.

1. *"I do have a primary doctor as well as my oncologist. I'm just surprised that my oncologist suggested it but really didn't give reasons why? He did say that it was showing good results for people like me but didn't get into what "people like me" are. Plus when I started researching it; it didn't seem to be for "people like me." I need to*

> *know what it is about me that makes me a good candidate. I thought I didn't have the traits they mentioned. So I asked to table it for 6 weeks so I can research it more; so we could have a deeper conversation. I do have severe asthma and the trial was so small. I'm not near ****, but there are many hospitals. I'm just wondering how to get a second opinion as I want to do the best I can for myself and not make a bad decision. I feel like they're throwing so many things at me without telling me the why? Thank you for replying."*
>
> 2. *"Dear ********* I'm so so so sorry to hear about your experience and I really feel with you. I keep fingers crossed that today's blood tests will not show you're anaemic (although from what you're saying it rather sounds as if you might be). I was explicitly told to report any unusual bleeding (that lasts for more than five minutes) - and from what you describe your bleeding has definitely been most unusual. Is there anyone - your oncologist a BCN - you could get in touch with about how this situation has (not) been handled? I understand the limits of protocol/tick-lists (they seem to be everywhere) but common sense is also needed especially if someone clearly is in need of help. I hope you won't have to deal with such a response from anyone in the team looking after you again. It's so hard to be in this situation and it makes it much harder to muster the energy to be your own advocate as well. I remember thinking that I really wanted my bleeding/period to have finished before starting the first round of chemo (I had had an emergency IVF and expected a heavy period); nobody else seemed really concerned about that but I think they should listen to what we're telling them too. We know our bodies best after all. Wishing you much strength (and good blood test results)"*
>
> 3. *"I would advocate for yourself and ask your doctor for a PET Scan."*

Box 2.

When patients decide against a doctor's advice on a medical matter, taking a more active role in their healthcare, they are yet again met with neglect in the absence of reassurance (see Box 3, #4). A user described feeling isolated in her medical decision because she "never got reassurance from the doctors" that there were others, like herself , "choosing quality of life". These doctors forgoed valuing quality of life over saving the patient. And in neglecting to reassure the patient, they instituted feelings of isolation and a sense of guilt for going against medical orders. The decision evaluation and following neglect are reminiscent of war metaphors. Cancer-related war metaphors are ubiquitous, staking the body as a "battleground" and the cancer as an "enemy" to be fought, with or without healthy casualties. These casualties take the form of healthy cells, energy, and other valued qualities, including those part of "quality of life"

mentioned by that user. And seemingly, any damage done to the body, or quality of life, is justified in the name of "saving" the person, and decisions made that deter from that goal are only hurdles, regardless of their reasoning (Kleinman, 2020). Though, we still see patients encouraging one another to play an active role, perhaps because they perceive to some extent this rigid end-goal in professional medicine, and understand their valuation is not a consensus standard. And as patients seek to play a more active role in their medical treatment, they also conceive of medicalization outside of medical professionality, in their own bodies, and as a community of patients. Encouraging and owning this personalized medicalization is further reflected in the topics pertaining to sharing remedies, resources and coping advice.

1. *"It can take all of my concentration and focus but if my mind starts to wonder I bring it back to the here and now. Life is so tough for us at the moment but worrying about what could happen makes it that much harder and life is certainly easier if you feel happier. It sounds like your second onc wasn t any more open to the statins than the first. I haven t seen mine to mention it to but I have been reading about it and have asked a friend who is a pharmacist to look into it. something I have done is start taking low dose asprin I know it s not proven to work as yet but there are lots of trials and it doesn t do any harm so I m thinking that why wouldn t I do all that I can? I guess in defence of the oncologists they are scientists who deal in proven facts and can t prescribe anything that hasn t gone through trials for that purpose however I feel that they should listen to us and not be dismissive. I will let you know of the reaction I get from my onc when I see her. I hope the run has helped to lift your spirits x"*

2. *"thank you. It was ok I guess. I am finding the oncologists very reluctant to discuss anything other than standard conventional treatment. I am interested in looking at some other drugs which maybe be useful in reducing breast cancer recurrence but are not currently used in breast cancer. I would just like to have a conversation without them rolling their eyes at me!She showed me the breast cancer predict thing for the first time which kind of freaked me out too seeing my prognosis as those little icons. I also found out I ll need three weeks rather than 1-2 radiotherapy as I d been told so by the time I went upstairs for my double dose chemo I was in a bit of a state. Have felt the usual rubbish after the Carboplatin too but I think i am coming out of it now and on the bright side that was my last carbo. 2 more Paclitaxol then onto the EC. It was my birthday on Saturday too. What a strange one. My family were wonderful my son made me the most beautiful card and my daughter made me an amazing cake. So lovely but hard not to have the thoughts of how many more I will be here for."*

> 3. *"I was very concerned about lymphadema going into the surgery and I felt that the doctors dismissed my concerns and I had to fight for information and care. I have three close friends who have had breast cancer and bi lateral mastectomies and they all have some level of lymphadema, so it's not as uncommon as doctors may lead you to believe. It is the only way that doctors have to determine the real spread of your cancer however. Hugs and good luck."*
>
> 4. *"@*********** I often wonder why our doctors don't support us that we are not the only ones that have stopped the medication. Sometimes I feel like I'm the only one that has decided not to take the medication but never get reassurance from the doctors that there are many of us choosing quality of life."*

Box 3.

Two topics, Specific Remedies (at home/OTC), and Medication Side Effects demonstrate "unprofessional" medicalization in medication. Users share personal experiences and take remedial advice generated not on the basis of scientific clinical trials, but on the past experiences and knowledge of those in a seemingly trusted peer patient group (see Box 4). The topic on Pain from Treatment and Medications takes a different angle on medication. Here, patients are finding advice on coping with painful side effects of treatment (see Box 4 #4-5). This is a notable topic because for cancer, "the treatment is worse than the disease" (Sontag, 1978). And with many patients feeling relatively "healthy" and asymptomatic upon diagnosis, *any* discussions surrounding pain are likely related to treatment and not the biology of cancer itself. Pain is tied to treatment, and treatment is, of course, tied to getting better. This connection between pain and approaching vitality exemplifies a biophysical incoherence, rejecting commonly assumed borders between living and dying[1]. Initially "healthy" seeming cancer patients seek wellbeing through a treatment course that inflicts upon them the most visceral image of death, *pain*. Interestingly, users in the forums see their pain consumptive of, and reflected in, the rest of their lives. One user commented that, while her doctors told her radiation treatments were "nothing to worry about", it had been the "worst week of her life", and connected her "emotions blow[ing]

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[1]

up" with her breast pain. Patients also find pain inhibits their ability to remain positive, a

sentimental direction deemed important for cancer patients. One user described her attempts to

"have joy in [her] heart" but the "constant pain wears" her down. Then, in the face of pain and

confused vitality, what *does* "health" look like?

1. *"I have been off the Arimedex for four months, joint pain is gone, I am sleeping again, no peripheral edema and my blood pressure is coming down closer to normal. The osteoporosis is another issue. I realize that by stopping this medication my risk for recurrence jumps up, but for me it is a quality of life issue. There is no doubt that the pandemic has severely affected all of us, but especially if you live alone and are older without nearby family. Whatever you decide is what is right for you is what you should do. I had the oncologist check my hormone levels when I recently had blood work done and they are quite low, but since there wasn't a benchmark taken before I started the medication, not sure what that exactly means but will have it checked again in October. The biggest risk is during the first two years after surgery, I had lymph node involvement, didn't do radiation or chemo, but so far am doing fine, my two years is up in December. Since I was told it would be "preventative" as my PET scan was normal, I opted out. I guess we all have to weigh our decisions on a personal level. I have no interest in trying another drug, they all have the same side effects or worse. Your neck issue could be tension, arthritis, or a bad pillow, just kidding. I wish you well, I finally started doing virtual visits with a psychologist to have someone to talk to and it has really helped."*
2. *"I fear radiation and it's long-term effects. Radiation seems to be par-for-the-course for those who have had lumpectomies. My preference is to have a treatment regimen that's personalized rather than "everyone gets this treatment". I would like to hear from others who have undergone radiation."*
3. *"Hello all Firstly thank you for creating this forum. Late August I was diagnosed with stage 4 MBC that has gone to @3 bones and through the skeletal system. Bone biopsy confirms BC in bones but PET shows the bones are not hypermetabolic where the breast & lymph are hypermetabolic. Im in Raleigh NC. My surgical & medical oncologist have ruled out surgery chemo & rad leaving me with one option Ibrance with an inhibitor. Ive read the trials (2016-17) on Ibrance and it seems like 79% of participants have lower immune responses. Firstly Like to know if anyone has feedback on a newer protocol/drug regime as this seems to have been developed 3-4yrs ago. And anyone have personal experience with Ibrance if they could let me know what their day is like quality of life. I understand everyones different… Im 68yrs living alone and this decision weighs heavy on my shoulders. Thank you for your responses.*
4. *I just want to share my experience. I use Kratom capsules from Kratom rank vendors from pain all the time. This method helps me a lot. Sometimes I also use kratom powder and add it to tea. It relaxes nerve cells and you do not feel pain. Kratom is just an amazing medicine!"*
5. *"Hi ******* thanks for the advice. Yes I don t know if lifting my mum or covid has*

> *caused a flare up or if the pain is nothing to do with lymphodeama. The area around*
> *my boob and arm pit has that full feeling though. I did see an NHS therapist last year*
> *but she didn t recommend any particular exercises and suggested I gently massage for*
> *10 minutes a day. I have the ***** exercise leaflet given to me after surgery but don t*
> *do them every day. Do you have a different exercise regime or can you recommend*
> *some exercises you have found helpful? I was discharged from the lymphodeama clinic*
> *but the orange peel skin on my breast has never cleared. Kind Regards"*

Box 4.

Health Conceptualizations

The topic of changed conceptions of health indicates some consciously changed perceptions of what health is for an individual. As a terminally ill patient, biophysical incoherence is a new standard. One can be in pain through healing, or feel as good as ever while dying. Good health is no longer simply being "not diseased", but a more nuanced idea interfolding physical and psychological sentiment, appearance, and ongoing medical prognosis. One user expressed annoyance because she "did not feel sick or experience any pain" upon her breast cancer diagnosis; she was "perfectly healthy" or so she thought. Now, in remission, she is worried about knowing if she is, in fact, healthy, wondering if she would have to "wait until having symptoms of any kind". A cancer diagnosis changes one's relationship to health by invalidating commonly understood indicators of good health. Seemingly, acclimation to this changed perception on health changes one's relationship to professional medical aid. The same user claimed she "knows" she will be "checked yearly with mammograms", briefly mentioning this as though to ward off any mentions of the obvious conventional method of tracking remissionary health. Not only does one need to seek out professional medical aid to "get better", they are also reliant on professional medical instruments to indicate if they are in good health.

Despite the essential role it plays, we know professional medicality is only part of a cancer patient's understanding of good health. After listing negative side effects of a medical

procedure, one user claims she still feels "healthy and good about [her]self", and that even on

bad days, she is "coping better" than she expected. She follows with prideful statements

regarding her active participation in medical decisions, saying she is "able to ask the right

questions," and is "not simply accepting" what she is told. This focus on asking the *right*

questions places perceived healing power in accurately understanding the illness and treatment

course. The same user does not understand the idea of her metastasis, refuses to let it "hit [her]

emotionally", and rather concentrates on "what is 100% verified". This suggests the patient's

desire for control and rejection of a potentially terrifying reality; instead she relies on the power

of accurate knowledge. Desire for control is generally reflected in patients encouraging active

participation in their healthcare.

Active patient participation is not necessarily limited to working against a doctor's

orders, and both can often be complementary. This leads us to the topics pertaining to approaches

to healing, the most popular being healthy living with treatment coupled with time. "Healthy

living" for patients is summarized by one user, who claims that her vitamins, healthy diet,

exercise (walking, yoga, and swimming) made healing from a bilateral mastectomy "no big

deal". Time plays an important role in this approach. While patients are granted a sense of

control, they are still reminded of the vital role of time and its healing powers.

The next, much less popular, approach to healing is described by the topic of accepting

one's diagnosis and following advice. Compared to the more active decision making role

beseeched by many, this approach is one of acceptance and least resistance (see Box 5 #1-3).

Arthur Frank's remarks claiming aggression was misplaced energy might best reflect this

approach. One user said she felt "fine" and did not "want to make a fuss". She expresses

discomfort with being labeled "brave", because she feels she has "no choice" and that "stamping

[her] feet is not going to change things". While she will follow what she is told, she is still

isolated in her experience and just wants to talk to someone who "feels the same". This

experience is relatable to others in the forum, who find the encouragement of "bravely" taking on

the challenge of cancer unhelpful and isolating (see Box 5 #4-6). Though, there are a few users

who take the third approach to healing, which is not only active, like the first, but also more

emotionally determined.

This third approach to healing is covered by the topic of being brave, which can involve

validating or honoring one's anger, sometimes by "fighting" the illness. Many who talk about

fighting the illness seem to already hold the experience of fighting for their treatment or fighting

to be understood by professionals (see Box 4 #7-8). One user subscribing to this third approach

began her comment by sentimentally declaring that "everyone here is a warrior," and that the

information was so "heartfelt." She soon after revealed that she herself was still "fighting for a

proper oncologist." Such external struggles already reflect combative and defensive opposition.

When experienced among preexisting pervasive cancer-related war metaphors, it is only natural

that conversations about healing take such an approach. Patients experience not only the act of

the body healing, but the entirety of their lives becoming a part of the experience. Being brave

and fighting become an instinctual determination fostered for one's survival against all struggles.

For some, the struggles also include a determination to stick around for loved ones, especially

children. One user imagined herself as a "warrior coming back from battle" while wearing a

chemo cap through airport security, approaching her two girls that "missed [her] a lot" and

welcomed her with "lots of love". She says they are her "reason to fight and stay positive".

While declaring this commitment to actively healing by fighting, she revealed how she felt she

was being perceived in public: respectfully, like a "warrior coming back from battle". This is

different from the shame often associated with cancer patients. Each of these three approaches

seem to indicate a conception of health and of healing with varying degrees of control. Though

often the control is just in appearances, either to make sense of one's experience or to put on a

show for others.

1. *"Aww I know that feeling. I had to have monthly meetings with my boss which I found very daunting. I'm sure it won't be as you imagine they'll just want to support you. I've found my confidence/self esteem has completely gone since my op not that I had a huge amount before it. It's very early still for you and a lot of adjusting understanding accepting and a bit of grieving is yet to be done. I really didn't understand all this a year ago and if I could pass anything on to you is to be kind to yourself. I know I ve made myself worse by struggling with guilt and frustration. Good luck lovey I d love to know how it goes xx"*

2. *"I think it must emotionally be hard to accept but on the positive you are so lucky that you have the op behind you and the surgeries to remove the cancer gone which is the most important thing. I find myself going from worrying about what they might find out to worrying about the after effects of the implant. A menu of worries! Thank you again for all the help as very strange to try and understand what s ahead of me.***** xx"*

3. *"Hi ****** I had a mastectomy in October 2018 and they wouldn't do an immediate reconstruction as I needed radiotherapy after the surgery. I was so upset about the thought of coming round from the surgery with only one breast. I pleaded for an implant at least but they said it could harden with radiotherapy and have to be removed. So I accepted it and with the help of talking with family and friends and advice from the lovely ladies on here I came to terms with it and comforted myself with the knowledge it was temporary. Best wishes xxx"*

4. *"You are hurting and that's normal. I have found that blogging has helped me to process everything I was and still am feeling through my investigations diagnosis and treatment. Once the treatment is over you can feel very abandoned but also guilty for not feeling on top of the world. Add to that the Covid-19 restrictions and loneliness and isolation and bam it really knocks you for six. You don't feel like a warrior or a survivor. You're just on the floor feeling battered and deflated. But you are still here sister and you will feel better with time. Cry as much as you need to. Then dry your eyes and notice how green the grass is and absorb the autumn colours. Just be for a bit. I find posting on forums like this helps too. Do you have children? I don't and some time ago I joined a support group for childless women which has helped me more than I could ever have imagined. Let me know if you want the details. Sending much love to you"*

5. *"I totally know what you mean about the friends thing. Some are genuinely amazing but I do feel let down by one or two who just haven't really been in touch or who ve done that "let me know if I can do anything to help" thing and then backed off. I still*

sometimes feel a sort of expectation that I'll be brave and strong so I don't really tell them a lot of what is on my mind. The lady who wrote the Ticking Off book and website covered this sort of thing off really well - about how some people just can't deal with it and others only really want to hear the "brave" "positive" "warrior" stuff so she would say "I'm fine" or "I m ok just a bit tired" and not really be honest about how she was feeling through chemo or emotionally. I found it helpful reading that because it felt familiar. I think this is why I find this forum so helpful because it's no holds barred and no judgment!"

6. *"I had my first zoom with a colleague from work last week (my first time 'seeing' anyone from work). This colleague is really lovely but she was tearful as soon as she saw my new look (ie scarf) and I ended up minimising all the side effects saying how easy I had found it how it wasn't that bad and leaving out all the bad bits to make her feel better. It makes me slightly concerned about seeing all the other colleagues at our team meeting - I find it difficult when people are tearful. You are both right we have had to dig deep to find the inner strength to cope with this."*

7. *"I was very concerned about lymphadema going into the surgery and I felt that the doctors dismissed my concerns and I had to fight for information and care."*

8. *"Everyone here is a Warrior. Brings tears to my eyes. All this information so heartfelt, but so diverse so hard to know what course, if any, to take, I'm not doing anything at this point, like Jane, listening to my body and being overall alert. Quality has to mean something. But it is a highly personal decision and certainly not easy. Sadly I'm still fighting for a proper oncologist, which I do believe is so important to all of us. I know we all pray for a cure, if they could do it with Covid, they can do it for us! Hang in!"*

Box 5.

Personal Relations: Appearances and Narratives

Appearances

Cancer has been resistant to aestheticization. Almost everything from tuberculosis to mental illness to plagues have been romanticized and those afflicted deemed "interesting", but not cancer (Sontag, 1978). Cancer patients are often shameful of their sickness, with some viewing it as equivalent to bodily decay. How then are patients and their illness experience affected by external appearances? I look to the topic of beauty for an answer. One user tells the story of ancient Egyptians who would mourn family deaths by shaving off their eyebrows, and sarcastically claims that then she herself is the "Queen of Sheba." We can assume that this user

lost her eyebrow hair in chemotherapy, and that she sees this physical appearance of hers as reflecting some internal state of mourning. Others have indicated that the change in external appearance marks a recognition of cancer's disruption of one's life, and also of their understanding of health. Recalling seeing old photos of herself, one user said she used to think she looked "rough." She goes on to say that she looks "nice and healthy" in the photos, and now after cancer treatment knows what "rough really looks like." We see external appearances here as a manner of understanding one's narrative. Whether for reflection of an internal state or for demarcation of change, appearance lies inside illness and life narrative.

Attempts to take control of an illness, even in acceptance, in a way make cohesive the biophysical incoherence narrative imposed by a cancer diagnosis. A cancer diagnosis disrupts a person's anticipated flow of life. They are now not sure what life holds for them, no longer feel secure in their health, and thus no longer in their expectations of the future.[2] This is reflected in the number of time-reflected topics including length and time of treatment, handling time off work, living life regardless of diagnosis, missing pre-cancer things, healthy living coupled with time, and settling into daily life. Any attempt to take control of one's prognosis is naturally an attempt to regain perceived control of life's temporality, whether in routine expectations, or in the longer term. Patients in the forum value this temporality, even in such simple ways as their personal placement in the timeline of all things. One user says all her medical procedures were "no fun" and quite "discouraging," but resigned to her "thankfulness" for them as they were unavailable to "others in the past." She places value in existing in the time that she does, even in the face of simultaneously living with cancer. This gratitude for the current time is further

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[2]terminal anticipation

reflected in users making the most of the present (see Box 6 #1-3), one user saying she is living "more in the present than the future" when considering spending money.

Of the time-related topics mentioned, the most popular were oriented to valuing future time (see Box #4-5). Users connected both the present and future to magnified valuations of life itself. They describe looking "forward to getting past all of this" as "life will seem more precious," or that they sometimes think they "are the lucky ones" because they "dont take days for granted." The commenter of the latter statement also mentioned not knowing "very many cancer patients that are just going through the motions of living." Clearly, there is an increased valuation of time, and an increased desire to seize control of narratives which are usually temporarily bounded, sometimes in appearance and other times in sensibility. How do patients describe these experiences and the experience of health online during COVID-19? Explicit coronavirus topics lend insight to this question.

1. *"hi [good] to hear from you too 💓thank you yes I m just taking one day at a time..im booked into a moving forward course on 5th October which I m looking forward to.Until then just enjoying what I can and living in the moment 🥰Sending hugs and love and you are so right we should be incredibly proud of ourselves xxxxx"*
2. *"What spurs me forward? I try to enjoy my yard, the gifts I have received from God and a little dog whose owner died in a car accident and needed a home. I had just put my 11 year old dog down and said, "no more dogs" because I was uncertain of my future. She literally landed in my lap and is such a joy. During these times when C-19 is such a big threat and the ability to socialize is diminished, living alone was not healthy for me, I needed Sadie. I have gotten much better at not doing "what if" and instead try to live for the moment and find the strength to deal with the future when it happens. I can't change it anyway."*
3. *"None of us knows how much more we have of life, so do our best and live each moment to the fullest. Let gratitude be a way of life."*
4. *"I'm due to stop tamox next month after 5 years on it. I am so looking forward to stopping and hope that it will mean my body will get back to normal e.g. I can bend without pain my knees won't keep giving way on me and are painful at times and hopefully I will just be able to move prior to starting tamox in 2012."*
5. *"Hello everyone. Hope you all our fine after all the family visits etc. I'm back at work*

> *tomorrow and to be honest looking forward to the rest!"*

Box 6.

Illness and Self COVID-19 Disruptions

I previously mentioned how terminally ill patients have a more complicated notion of

"good health" that interfolds physical and psychological sentiment, appearance, and ongoing

medical prognosis. The pandemic complicates this idea, not simply because of higher risk of

COVID-19 infection itself, but with a plethora of added stressors and dimensions imposed by

public safety measures. Pandemic-related topics cover user stories of virtual healthcare (sitting

all day, telehealth visits, zoom meetings), breast cancer treatment after being infected with

COVID, postponements of medical procedures, and patients actively ignoring or missing

medical appointments. Patients are discussing how COVID-19 infection or pandemic-related

delays would affect their treatment(see Box 7 #1-2). While discussions about delays were

prevalent, users' responses to these disruptions in their medical routines were often not

distressful. Some users even claimed to enjoy not needing to visit a doctor as much (see Box 7

#3). The topic of actively ignoring or missing medical appointments evinces relief found in

disrupted medical routine and also fear of COVID-19 (see Box 7 #4).

1. *"Yes, it was found during a routine mammogram I delayed my annual screening because of COVID, especially given the local reluctance of a good segment of the people to adhere to standard cautions (masking, distancing), but the surgeon said it may not have made a difference. The cancer might have been too small to detect during my due mammogram, so in a way it sort of worked out."*
2. *"Hello, this could be the hardest part of the journey, the waiting. I would think 2 months is a long time. I know there is the holidays and struggles with staffing and covid, but have you considered asking your doctor why there has been such a delay in getting answers and treatment? Has the doctor mentioned any treatment options. With MBC I have a much harder time being patient, it definitely changed my sense of urgency."*

> 3. *"That's interesting that ******* do a telehealth check much better than having to keep going to the hospital and waiting around there."*
> 4. *"I don't have any appointments with any doctor scheduled, I almost breathed a sigh of relief when I realized it. It might be nice to just slide for just a little while (not too long). It has been years since I didn't have any appt. to be anxious about."*

Box 7.

What is even more notable is the topic of COVID-19 forcing patients to do their own health research. We have already observed in the users an inclination to play a more active role in healthcare, but the pandemic seems to have lent patients an additional opportunity for such activity. One user described how "because of covid", she was "forced to do [her] own research" and was "so glad [she] did." She is affirmed in doing this research whenever she asks her oncologist a question that they could not answer, but that she, herself, could. Finding health information online generally became commonplace after the pandemic imposed the internet and media as the primary sources for public health information. Increased participation in seeking health literacy online during the pandemic was noted a number of times in the forums(see Box 8). Patients have found a different relationship with their illness through research that is mostly done online. The topic of COVID forcing patients to do their own health research stands alone. There were no topics in the model indicating health-literate discernment in research. While there are conversations being had about increased health literacy, there are not as many on how to evaluate resources found in the process of researching.

One user said that all of the support groups in her area had shut down with the pandemic, and so she used some on Facebook that she found "very informative." She confided in others about the emotional week she was having. It was in these online communities filled with user-provided medical information that she sought an alternative support network to those she lost due to the pandemic. Pandemic-imposed quarantine forced many into similar situations of

isolation. The effects of this isolation uniquely affected cancer patients, who are already isolated

in many ways that will be evaluated in the following section. These effects are reflected in the

latter of the topics of fear of covid/coping with covid conditions and oncological psychology for

isolation. It is not simply a matter of being individuals who are isolated like everyone else is, but

of specifically being cancer patients who are isolated, and the impacts this is having on them

psychologically, hence the term *oncological psychology*. Becoming isolated as a breast cancer

patient is to have one's experience less often shared by others, individualizing one's illness

further. Though, some users suggested a level of comfort in knowing others are finally sharing at

least their experience of isolation, even if for different reasons.

1. *"Good grief what a voyage! Because of covid, I forced myself to do my own research and so glad I did. Every time I have another onco call, I throw her a question that throws her off and she says she is not sure and cant provide an answer. I already know the answer and just want confirmation. It is my surgeon that has been the most upfront with me. For me, covid delay were a sort of blessing that allowed me to dig in and find my own answers..... I wish you nothing but the best, this site is a blessing of its own."*
2. *"After weighing the options and considering that it seems everyone is "treated" the same, for me I made the right choice. Question everything, do your research and go with what you decide is best for you. My hormone levels weren't checked before I started the Arimidex or during the treatment. When I asked to have them checked they were lower than what is normal for my age and have only gone up slightly in eight months. I was told the test is accurate, so I wonder why it isn't done before treatment is started. At any rate, I am going to try to enjoy each day and enjoy my good health, and deal with the Fear of Recurrence that someone mentioned is an actual "condition"."*
3. *"Cancer is systemic and isn't the result of one thing so having drunk or not having drunk alcohol isn't the only factor. Research shows it does increase your risk of developing or recurrence of breast cancer. The same with sugar there is now no doubt processed sugar is a promoter of cancer if you think the research isn't conclusive then ask how often over recent years have you seen research saying sugar doesn't promote cancer? Dairy cow in particular is another...I don't understand when research is from a reputable source and repeatedly coming out how we can afford to just ignore or dismiss it surely it should be respected and considered? Then if it isn't for you fair enough ignore it but make an informed choice knowing the facts."*

Box 8.

Illness in a Social Context

In the illness in a social context section, intragroup support captures how patients relate their experience to illness-external social areas like community, while appearances and narrative show the role patients assume in presenting their illness and experience to others. Alex Broom's (Broom et al., 2019) delineation of individualistic paradigms used so often in discussions surrounding cancer explain the importance of exploring breast cancer in a social context. These paradigms obscure how cancer emotions operate relationally "between bodies, subjects, discourses, and practices", which are all intertwined with circulating beliefs and culture. Thus, patient experience in sociality is vital to understanding illness narratives.

Social Relations: Intragroup Support

Before exploring group experiences, I would like to establish the norms subscribed to by the users of the forums. To establish these norms is to make clear the common ground upon which patients learn to be a member of the online community. I turn to three topics regarding explicit group bonding: active group building (introductions, encouraging connections), explicit bonding and relationship building within group, and reflecting on positive sociality. Active group building includes the normativity of introducing yourself upon entrance to the group, providing some back story, usually followed by some enthusiasm. These introductions are met with comments encouraging connections between members (see Box 9). Explicit group bonding and relationship building involves activities prompted for the explicit purpose of creating a sense of community. Upon running initial analyses of the data, I found various data entries with only a single word in all caps. I later realized these single word entries were part of a word association game, one of many word "games" played as a group, which contribute to this sense of community. This is just a single example of such group activities. Reflecting on the positive

sociality found within the group reflects satisfaction with what the group is, and what it means to members.

Evidence of successful group cohesion using these norms are seen in several topics. The first of these is sharing stories for specific advice. Trusting a group enough to share one's experiences, and even asking the group for advice indicates cohesiveness in the form of vulnerability. This trust is fostered with the topic of inquiring about one another (wellbeing, personal life), where people can show a personal investment in another person in the group. The topic of financial conversations also indicates a level of trust within the group, as financial matters are usually considered a private matter. Perhaps the anonymity of the internet allows for such open communication on private affairs. Though, it also seems that how people's stories are received from others is an important part of this trust.

Often, empathy models depend on abstracting nuance from individual experience to provide dissimilar others with an adapter of sorts, to safely connect to someone's suffering without doing the emotional work of actually sharing their experience. Users on the forum are typically breast cancer patients who share the common experiences of modern day cancer treatment. They not only share the experience of the treatments themselves, but also the illness' ripple effects on the rest of their lives. Members of the group often find others with relatable experiences and are able to connect with personal tales. They are not using models of understanding emotionality to connect with others, but their actual life experiences. In being able to understand to such a personalized extent the struggle of others, users are also able to provide meaningful advice on two topics: living a smooth life logistically, and handling external relationships (mother/daughter, etc.).

In the topic of the process of getting doctor advice, one user recalled a doctor "disregarding [her] pain" from therapy as "just part of the process." This invalidating manner of understanding a patient leaves them isolated, unable to share their experience without a true witness. A true witness is one that recognizes a person's suffering outside dimensions of expectations. Expectations in illness come from clinical observations that blanket nuanced suffering into buckets of general emotionality[3]. But in the setting of this forum, others receive accounts of illness experience enthusiastically, often emotionally thanking one another for sharing their stories. This is seen in the topic of general expressions of gratitude for sharing/helping. Thus, appreciation completes the cycle of story sharing with celebration among true witnesses, rather than with the abstracted disregard users receive from nonpatients(see Box 9). And sharing illness experience becomes an act of connection, and not of silencing shame or isolation.

---

1. *"That's fantastic news so pleased for you and thank you for sharing! Long may the good results continue xxx"*
2. *"@*******, thank you for sharing your experience with all of us. It sounds like you are getting very good care. I wish you the very best, and a speedy recovery. We are here for you!"*
3. *"Thank you ******, for sharing this. After 18 months of harsh chemotherapy And no treatment end in sight, I can relate to the questions of quality vs quantity of life. I had a couple thoughts about your post. Are you planning to go into home hospice or a hospice house? If a hospice house, that is where you would spend your final days, not in a hospital. I have had 2 dear ones die of cancer in hospice houses and both experiences were comfortable and kind to all involved. This is my choice when the time comes. I do not want to die at home because I want my loved ones to not have to worry about anything except enjoying final time with me… Peace and all good in this journey."*
4. *"Oh, thank you for your kind words, ***! I'm sorry you had to go through the ordeal and pain but am very to happy that you are on the mend and found a way to help heal. Thanks for sharing. I feel better just knowing I'm not the only one. Blessings to you!"*
5. *"Thank you for sharing this…The journey begins, I applaud your courage."*
6. *"@********* thank you. Your reply made me feel a lot better. I think you are right I*

---

[3] @ will i think

> *ve got no idea what s going on in my body with all the emotion anxiety chemo and possibly the start of menopause too. It just feels like I've still got a mountain to climb and then the real race will start which is where I am meant to start living again. This is the bit that fills me with terror. I know no one can tell me it s going to be ok but it s the one thing I long for. dealing with what you know is fact os the best thing but so so difficult to achieve. I am so grateful for this forum it helps me so much to have you amazing ladies to turn to. Xxx"*
>
> 7. *"Breast cancer IS very isolating. I don t think anyone really understands the complexities physical and emotional so unless you are fortunate to have a friend who's been through it you kind of educate friends and support as you go along. I too went through all my treatment without crying. I even spent four days in isolation with neutropoenic sepsis and couldn't see what the fuss was about. It s a powerful defence to help us get through but the emotions and fears are still there locked away ready to find the cracks just as you hope to get a break from the blessed thing.Unfortunately end of treatment also means end of medical support - see your GP. In the current circumstances it s impossible to see your GP unless it s a dire emergency and who can describe a broken spirit after you've been seen going through hell without tears?You still have access to your breast cancer care nurse and I think you should contact her and tell her exactly what you've said here. You are by no mean the only one and it is harder during the pandemic with support services postponed but she may know of online support."*

Box 9.

Social Roles: Appearances and Narratives

If sharing illness experience is so widely unbeared by true witnesses, what are patients sharing to others outside the group? If not the true holistic depths of experience, what are patients letting appear for others to conceive? The topics of gift giving/special occasions and celebration/being strong for loved ones show users discussing how they are being strong, or at least appearing so, for loved ones. After having a bilateral mastectomy, one user expresses confusion as to how her mom was able to handle it so well when previously undergoing the same treatment. She says her mom explained to her that "she was bothered and that she hid her emotions from [the family]," which she says is characteristic of her mom. Another user shares that she loses sleep at night feeling unable to talk about the "what if" with anyone because her

husband "does not want to talk about" it. Denial of the big, scary *"what if"* of death, is so profusely accepted as a normal *need* for cancer patients and loved ones to cope with a diagnosis. If we accept denial as a *response* and not a *need[4]* we see how patients who only respond with denial, but do not need the denial, are silenced, isolated, and harmed. The user whose husband "does not want to talk about the what if" leaves his wife to respond with the same silence, but only externally. Internally, she experiences a struggle that keeps her alone, awake at night. The patients mentioned in both comments were disallowed the company of others in their experience. We see appearances in the illness and self section to be manners of understanding one's narrative. Here in the social context, however, we see the enactment of appearances, like putting on a brave face, are an effort to present a less painful narrative to others.

Illness and Sociality COVID-19 Disruptions

Physician patient relationships are already restricted by professional boundaries that disallow a physician from holistically caring for the patient. These boundaries mandate disease talk to facilitate the commercial administration of medical care[5]. During the pandemic, these boundaries strengthened, and new barriers formed. Relevant topics include Zoom conversations/online emotional support resources and sharing external resources/talking about sharing own experiences (see Box 10 #1-2). Zoom conversations often pertained to telehealth appointments. The existing disconnect between physician and patient in current healthcare, coupled with the lack of in person accountability, left patients further disconnected (see Box 10 #3). One user even admitted "essentially falling through the cracks of covid," letting herself "be invisible to many of [her] doctors who are too overwhelmed with everything to really notice."

---

[4] @will
[5] maybe .. pt to smth?

While disconnections seemed to pervade physician patient relationships, there was a different

attitude towards the pandemic's effects on the public at large. Because of the public safety

guidelines, everyone was experiencing isolation and fear of sickness, just as cancer patients

already were (see Box 10 #4). One user passively remarked that everyone finally knew "what

we've been going through," implying relief for the long awaited company of non-patients in their

experience. The pandemic seems to have given light to the existing experiences of breast cancer

patients, but also to worsening ones in the shift to online healthcare.

---

1. *"Thanks for organising the zoom calls it's been great to chat with you all. Great that we can keep in touch and support each other going forward too. Good luck with work. ******x"*
2. *"We had a zoom call with the girls to open presents together - hastily posted parcels had arrived in time! - which was really lovely."*
3. *"It is amazing that all your oncologists still keep in contact with you. Due to covid, and my inability to take any of the AIs or tamoxifin due to side effects and my osteo, I have not seen or heard from my oncologist after my first mammo. I only see my dr once every 6 months now, and I tell him what tests I would like."*
4. *"The zoom calls have become a regular weekly event for us all so we're probably more in touch than before COVID!**** enjoy your gardening and hope the weather has improved where you are.Hope all of you and yours are all keeping well.***** x"*

Box 10.

CONCLUSION

This thesis uses two online breast cancer patient forums as data sources to delineate patient illness narratives during the COVID-19 pandemic. Using topic modeling, I modeled large amounts of data, pulling the most relevant topics of conversation among the forum users. Various topic models were operationalized, motivated by four realms: medicality, emotionality, healing, and pandemic times. Numerous dimensions of illness narrative were revealed in the results, which fell into one of two groups, either roles or relations. This thesis garners an anecdotal and relational understanding of communal illness narratives, moving beyond existing research that reductionarily focuses solely on specific individual illness experiences. Using this understanding, it gleans how breast cancer patients have communally adapted their illness narratives in the face of the pandemic.

Separating illness and self from illness in a social context was key to determining which general themes found by the topic models were roles, and which were relations, in the grand scheme of illness narrative. Roles played in one's own illness revealed a fervor for control over one's health, describing varying extents to which an active effort was expected in one's illness experience. Here we see a tension between professional medicine and personal understandings of health, shifting legitimized medicality towards patients and away from physicians. It is important to note the cause of this shift is cited to be disconnect with doctors, either in trust or in value misalignment between patient and physician.

Misalignment continues to disrupt other naturally occurring relations, including that between vitality and death in the form of biological incoherence. As patients seek to be healed to normal vitality through allopathic means, their bodies incur damages representative of death, including pain and bodily "decay." And as this biological incoherence renders normal indicators

of good health meaningless, one's understanding of health is complicated. Assurance of good health becomes reliant not only on tools of professional medicine, but also on one's personal relation to the illness experience—how much perceived control a patient has over their illness. Varying levels of perceived control are outlined by the three approaches to healing, each of which is motivated by different external circumstances. The active approach coupled with time is highly motivated by a belief in the healing power of time. The passive approach is motivated by a surrenderance to the natural illness experience, and a simple desire for relatable company in that experience. The emotionally active approach is reflective of an external struggle for support, which when combined with pre-existing prolific cancer war metaphors and desires for respectability lead to a similar approach to healing from illness.

Found relations to one's own illness reveal an interpretive relationship between illness and one's understanding of life narrative. Appearances are part of a narrative, as either reflective of an internal state, or marcation of change. Generally, the disruption of temporal narrative and anticipation of the future leads to attempts to cohesify parts of the narrative, including biological incoherence, by seeking active participation in one's illness experience. On the other side of active participation, surrender to this disruption is seen in the increased valuation of time, both present and future.

Interestingly, patient relations in a social context involved finding community among other users, true witnesses, and finding loneliness among nonpatients, false witnesses. Honest accounts of experiences are welcomed and celebrated on the forums, while they are discouraged offline. Reduction is expected of patients when recounting their internal struggles and experiences to nonpatients. Patients must reduce their experiences to biology when talking to doctors through disease-talk, and must reduce their experiences to bravery through masks of

active participation and positivity when talking to loved ones. The responsive complimentary attitudes given by others then reinforce this reduction, leaving only blanket models of emotional understanding or medical expectations as a means through which to connect with the patient. This multifold reduction eliminates opportunity for a loved one or caregiver to be a true witness to the patient's narrative. Hence, offline, patients are disallowed the true company of others in their experience. And who is this for? It might be argued that a patient finds comfort in comforting those that they love. But do we not owe those suffering the dignity and bravery of sharing in their experience? Do we not owe them the consideration of not isolating them in their struggle? Do we not owe them, and ourselves, the forgoing of our own emotional comforts to grant the relationship the stronger bond that such an honest connection could gift?

There is a relief and surrender to be found in true witnesses. Patients found long awaited company in their isolation as cancer patients at the onset of COVID-19 among the general population, as well as among their (often) newfound online patient communities. They finally found others sharing in at least parts of both their illness experience and disrupted illness narratives. Truly experiencing what it is to live in isolation is almost the easiest way to surpass the gaps in connection instituted by the reductionary standards of sharing.

The previously mentioned tension between patients and professional medicine is only furthered as disconnect between patients and physicians increased in the shift to telehealth and remote care. Patients found relief in disruption of the relentless external medical process of healing imposed by these doctors, and often felt even less understood by doctors over video calls. Now with more time to be online, patients valued doing their own research, defocusing profesional medicine as a source of information about one's illness and illness experience.

The studied forums themselves are alternative sources of information. Again, it is important to recognize that while an increased desire for health literacy was seen, there was no matched emphasis applied to e-health literacy discernment. Of course, health forums can be sources of harmful medical information, or of harmful sociality. For this reason, it might be argued that focusing research efforts on such forums and subsequently potentially contributing to increased popularity of the forums could be harmful. Other research-related limitations of health forums specifically with the natural language processing methods used in this thesis include the vulnerability of model overfitting, lack of consideration for abbreviations and slang, and the general lack of gold standards and annotated colloquial data to reduce subjectivity and ambiguity in topic model interpretation.

However, topic modeling still provides a more standard means to analyzing large amounts of textual data, regardless of the bias present in final model interpretation. And despite the potential harms of misinformation on the forums, forums still provide a place for patients to find not only disease-talk aid, but also both illness-talk aid and community. They are a place of support, community, and more for patients, and should thus be further studied by sociologists and medical professionals. There is value to be gained in these forums, where patients are able to be honest about their illness experience, and where a true group illness narrative can be conceived. The forums provide a central location for thousands of patients to collectively work to make sense of, put words to, and validate their illness experience. Forums have the ability to propel deeper understanding of patient narratives, as well as how these patients would like others to approach understanding these narratives.

We have seen through various angles of roles and relations sick people assume that illness is relational—relational to the self, the disease, time, others, and more. Focusing just on medicality reduces a patient and this relationality to almost pure biology. Patients assume multiple roles, making sense of and creating narratives to achieve various context dependent goals. By understanding these goals, we have seen it is possible to better understand how patients interact with their illness, life, and others. It is not only the patient outcomes that are valuable, but also the entire conception of an illness narrative. In deepening our understanding of this conception, we can approach providing more tactful support to patients. And if nothing else, we can *at least* bear true witness to their experiences, and perhaps, in the process, learn something about ourselves, our health, time, life, love, and more.

APPENDIX

Topic Model Distributions

1. Medicality Topic Model Distribution

1	0.017*"question" + 0.016*"stori" + 0.014*"breast" + 0.014*"support" + 0.013*"forum" + 0.013*"share" + 0.013*"http" + 0.013*"inform" + 0.011*"*******" + 0.010*"group"
2	0.026*"cord" + 0.026*"oncotyp" + 0.022*"exemestan" + 0.014*"inform" + 0.012*"switch" + 0.011*"crazi" + 0.010*"radiat" + 0.009*"open" + 0.009*"medic" + 0.009*"concern"
3	0.019*"yoga" + 0.014*"anastrazol" + 0.013*"paclitaxol" + 0.012*"heal" + 0.011*"class" + 0.011*"sarah" + 0.010*"medic" + 0.009*"pictur" + 0.009*"bodi" + 0.009*"exercis"
4	0.031*"share" + 0.016*"appreci" + 0.015*"continu" + 0.011*"wish" + 0.011*"best" + 0.011*"debilit" + 0.010*"kind" + 0.010*"thank" + 0.010*"experi" + 0.009*"word"
5	0.010*"breast" + 0.010*"surgeri" + 0.009*"mastectomi" + 0.008*"lymph" + 0.008*"nod" + 0.008*"reconstruct" + 0.007*"node" + 0.007*"remov" + 0.007*"radiat" + 0.007*"surgeon"
6	0.005*"love" + 0.004*"hair" + 0.004*"today" + 0.004*"work" + 0.004*"start" + 0.004*"better" + 0.004*"need" + 0.004*"day" + 0.004*"treatment" + 0.004*"help"
7	0.021*"articl" + 0.020*"inhibitor" + 0.017*"seek" + 0.016*"connect" + 0.014*"thin" + 0.013*"program" + 0.012*"anastrozol" + 0.011*"experi" + 0.010*"interest" + 0.009*"symptom"
8	0.009*"breast" + 0.007*"treatment" + 0.006*"inform" + 0.005*"oncologist" + 0.005*"diagnos" + 0.005*"team" + 0.005*"question" + 0.005*"doctor" + 0.005*"support" + 0.005*"group"
9	0.027*"helplin" + 0.021*"open" + 0.015*"saturday" + 0.014*"nurs" + 0.012*"talk" + 0.012*"board" + 0.011*"data" + 0.011*"free" + 0.010*"friday" + 0.008*"close"
10	0.016*"rubi" + 0.013*"liver" + 0.013*"doctor" + 0.010*"recommend" + 0.009*"opinion" + 0.008*"book" + 0.007*"write" + 0.007*"medic" + 0.007*"size" + 0.006*"imposs"
11	0.021*"maggi" + 0.013*"therapist" + 0.013*"health" + 0.011*"walk" + 0.010*"financi" + 0.007*"number" + 0.007*"opt" + 0.007*"worth" + 0.007*"massag" + 0.006*"small"
12	0.030*"cough" + 0.022*"insur" + 0.020*"mari" + 0.014*"asthma" + 0.011*"shape" + 0.011*"answer" + 0.011*"cover" + 0.010*"foot" + 0.010*"peppermint" +

	0.009*"constant"
13	0.023*"awesom" + 0.016*"help" + 0.016*"bike" + 0.015*"repli" + 0.013*"care" + 0.011*"brand" + 0.011*"thank" + 0.011*"studi" + 0.010*"****" + 0.009*"appreci"
14	0.018*"facil" + 0.013*"safe" + 0.013*"sensit" + 0.011*"idea" + 0.011*"marker" + 0.010*"tumor" + 0.010*"unit" + 0.010*"mouth" + 0.009*"problem" + 0.009*"rubi"
15	0.043*"thank" + 0.021*"great" + 0.019*"info" + 0.015*"suggest" + 0.012*"mini" + 0.011*"heart" + 0.011*"help" + 0.010*"june" + 0.009*"beauti" + 0.009*"love"

2. Emotionality Topic Model Distribution

1	0.004*"work" + 0.004*"start" + 0.004*"help" + 0.004*"treatment" + 0.004*"need" + 0.004*"support" + 0.004*"friend" + 0.004*"today" + 0.004*"year" + 0.004*"have"
2	0.018*"record" + 0.009*"physic" + 0.009*"health" + 0.007*"distanc" + 0.006*"walk" + 0.006*"help" + 0.006*"situat" + 0.006*"smooth" + 0.005*"healthi" + 0.005*"expens"
3	0.026*"https" + 0.025*"group" + 0.021*"support" + 0.016*"inform" + 0.013*"forum" + 0.013*" **************" + 0.012*"breast" + 0.012*"help" + 0.011*"http" + 0.009*"connect"
4	0.016*"marker" + 0.015*"feedback" + 0.010*"****" + 0.008*"interest" + 0.008*"info" + 0.007*"countri" + 0.007*"cycl" + 0.006*"hug" + 0.006*"great" + 0.006*"sound"
5	0.021*"lewi" + 0.017*"belinda_f" + 0.015*"massag" + 0.015*"fanci" + 0.011*"juic" + 0.009*"doctor" + 0.008*"cake" + 0.007*"radiat" + 0.007*"mean" + 0.007*"bath"
6	0.041*"bench" + 0.021*"fiona" + 0.019*"everybodi" + 0.018*"camp" + 0.017*"girlfriend" + 0.015*"sure" + 0.007*"retir" + 0.007*"appoint" + 0.007*"forum" + 0.006*"schedul"
7	0.019*"favourit" + 0.015*"doc" + 0.009*"kind" + 0.008*"anastrozol" + 0.008*"qualiti" + 0.007*"stop" + 0.007*"doctor" + 0.006*"year" + 0.006*"wonder" + 0.006*"take"

3. Healing Topic Model Distribution

1	0.009*"best" + 0.007*"healthi" + 0.007*"physic" + 0.007*"brave" + 0.006*"meantim" + 0.006*"health" + 0.006*"emot" + 0.006*"addit" + 0.006*"mastectomi" + 0.005*"cost"
2	0.006*"work" + 0.005*"love" + 0.005*"need" + 0.005*"year" + 0.005*"help" + 0.005*"surgeri" + 0.005*"start" + 0.005*"thank" + 0.005*"treatment" + 0.004*"tell"

| 3 | 0.026*"radiat" + 0.016*"https" + 0.014*"breast" + 0.013*"inform" + 0.012*"anastrozol" + 0.011*"connect" + 0.011*"****" + 0.011*"doctor" + 0.011*"heal" + 0.010*"medic" |

4. Pandemic Time Topic Model Distribution

1	0.016*"recov" + 0.009*"treatment" + 0.008*"know" + 0.008*"isol" + 0.008*"cell" + 0.007*"learn" + 0.007*"hard" + 0.007*"fair" + 0.007*"sens" + 0.007*"stuff"
2	0.009*"radiat" + 0.009*"heal" + 0.008*"scar" + 0.007*"link" + 0.007*"gelbel" + 0.006*"pressur" + 0.005*"boob" + 0.005*"fall" + 0.005*"drop" + 0.005*"similar"
3	0.015*"screen" + 0.013*"mammogram" + 0.012*"dose" + 0.011*"coronavirus" + 0.010*"social" + 0.010*"pandem" + 0.009*"delay" + 0.008*"second" + 0.008*"impact" + 0.008*"answer"
4	0.012*"breath" + 0.009*"oncologist" + 0.009*"member" + 0.009*"work" + 0.009*"depend" + 0.008*"healthi" + 0.008*"crazi" + 0.007*"call" + 0.006*"main" + 0.006*"amaz"
5	0.026*"radiat" + 0.016*"breast" + 0.014*"nurs" + 0.010*"group" + 0.009*"later" + 0.009*"hello" + 0.009*"pandem" + 0.009*"collect" + 0.008*"year" + 0.008*"support"
6	0.005*"chemo" + 0.005*"treatment" + 0.005*"good" + 0.005*"work" + 0.005*"thank" + 0.005*"love" + 0.005*"know" + 0.005*"mask" + 0.004*"say" + 0.004*"tell"
7	0.013*"condit" + 0.009*"quarantin" + 0.009*"happi" + 0.008*"vaccin" + 0.008*"believ" + 0.007*"lung" + 0.007*"problem" + 0.007*"rule" + 0.007*"drug" + 0.007*"mask"

5. Forum 1 Medicality Topic Model Distribution (M)

1	0.018*"year" + 0.017*"treatment" + 0.016*"mammogram" + 0.016*"****" + 0.016*"week" + 0.015*"second" + 0.014*"opinion" + 0.013*"symptom" + 0.013*"clinic" + 0.013*"inform"
2	0.016*"effect" + 0.016*"anastrozol" + 0.016*"month" + 0.015*"hair" + 0.015*"take" + 0.013*"exemestan" + 0.013*"pain" + 0.012*"repli" + 0.012*"bone" + 0.012*"joint"
3	0.024*"support" + 0.023*"thank" + 0.022*"activ" + 0.022*"group" + 0.021*"interest" + 0.018*"fatigu" + 0.016*"care" + 0.016*"respons" + 0.014*"tumor" + 0.014*"local"
4	0.034*"question" + 0.028*"advic" + 0.026*"great" + 0.023*"concern" + 0.022*"night" + 0.021*"love" + 0.019*"thank" + 0.017*"know" + 0.017*"number" + 0.016*"stay"

5	0.018*"breast" + 0.015*"surgeri" + 0.013*"lymph" + 0.013*"nod" + 0.011*"surgeon" + 0.011*"pain" + 0.011*"radiat" + 0.011*"time" + 0.010*"start" + 0.010*"follow"
6	0.032*"thank" + 0.031*"info" + 0.031*"share" + 0.021*"stori" + 0.021*"experi" + 0.020*"coupl" + 0.018*"wish" + 0.016*"suggest" + 0.016*"advic" + 0.016*"post"

6. Forum 2 Medicality Topic Model Distribution

1	0.017*"info" + 0.009*"servic" + 0.008*"includ" + 0.007*"shefgirl" + 0.007*"asap" + 0.007*"wrong" + 0.006*"inform" + 0.005*"believ" + 0.005*"regard" + 0.005*"sure"
2	0.036*"scalp" + 0.030*"mountain" + 0.026*"xxxxx" + 0.024*"scarf" + 0.022*"side" + 0.020*"spell" + 0.019*"lash" + 0.015*"brow" + 0.014*"bath" + 0.010*"salt"
3	0.033*"antihistamin" + 0.029*"tnbc" + 0.009*"wish" + 0.008*"chicken" + 0.008*"kind" + 0.008*"team" + 0.007*"check" + 0.006*"fantast" + 0.006*"lucki" + 0.006*"hug"
4	0.014*"advic" + 0.011*"sarah" + 0.009*"jowel" + 0.008*"human" + 0.008*"appreci" + 0.007*"tough" + 0.007*"option" + 0.006*"donkeywoman" + 0.005*"primari" + 0.005*"feet"
5	0.017*"idea" + 0.008*"fabul" + 0.006*"add" + 0.006*"that" + 0.006*"reliev" + 0.005*"list" + 0.005*"anxieti" + 0.005*"pant" + 0.005*"chat" + 0.005*"write"
6	0.059*"throat" + 0.028*"gain" + 0.025*"sensat" + 0.024*"schedul" + 0.022*"salli" + 0.017*"mouth" + 0.006*"afraid" + 0.006*"ulcer" + 0.005*"diet" + 0.005*"zoom"
7	0.034*"constip" + 0.034*"diarrhoea" + 0.026*"lung" + 0.024*"bleed" + 0.024*"tired" + 0.023*"sepsi" + 0.020*"neutrophil" + 0.016*"heavi" + 0.014*"last" + 0.014*"emerg"
8	0.021*"travel" + 0.019*"hadn" + 0.019*"routin" + 0.015*"success" + 0.015*"bench" + 0.014*"supermarket" + 0.014*"brother" + 0.014*"boy" + 0.013*"freez" + 0.013*"rosi"
9	0.031*"review" + 0.010*"cake" + 0.008*"shefgirl" + 0.007*"xmas" + 0.006*"usual" + 0.006*"alcohol" + 0.006*"sarah" + 0.006*"intend" + 0.005*"jane" + 0.005*"haha"
10	0.026*"https" + 0.020*"******" + 0.019*"guid" + 0.017*"inform" + 0.015*"forum" + 0.015*"hydrat" + 0.014*"http" + 0.014*"introduc" + 0.014*"communiti" + 0.013*"lifeafterlola"
11	0.004*"love" + 0.004*"work" + 0.004*"start" + 0.004*"treatment" + 0.004*"hair" + 0.004*"today" + 0.004*"need" + 0.004*"better" + 0.003*"have" + 0.003*"day"
12	0.039*"vein" + 0.027*"thrush" + 0.024*"ultrasound" + 0.021*"difflam" + 0.020*"novemb" + 0.020*"invas" + 0.019*"fortnight" + 0.019*"ulcer" + 0.018*"starter" + 0.018*"cannula"

7. Forum 1 Emotionality Topic Model Distribution

1	0.041*"talk" + 0.035*"journey" + 0.034*"happi" + 0.030*"year" + 0.029*"friend" + 0.026*"feel" + 0.026*"good" + 0.024*"get" + 0.023*"think" + 0.023*"start"
2	0.080*"group" + 0.067*"support" + 0.038*"breast" + 0.038*"tell" + 0.034*"help" + 0.033*"surgeri" + 0.030*"lymph" + 0.029*"check" + 0.025*"covid" + 0.023*"doctor"
3	0.078*"great" + 0.072*"drug" + 0.057*"effect" + 0.038*"agre" + 0.038*"scan" + 0.033*"oncologist" + 0.030*"friend" + 0.027*"get" + 0.027*"pain" + 0.026*"****"
4	0.071*"sure" + 0.051*"care" + 0.031*"work" + 0.030*"agre" + 0.028*"listen" + 0.027*"decis" + 0.027*"effect" + 0.025*"learn" + 0.025*"read" + 0.023*"best"
5	0.041*"inform" + 0.037*"radiat" + 0.033*"breast" + 0.027*"week" + 0.026*"mastectomi" + 0.026*"feel" + 0.026*"felt" + 0.024*"surgeri" + 0.024*"leav" + 0.022*"visit"
6	0.046*"pain" + 0.046*"medic" + 0.039*"doctor" + 0.034*"year" + 0.034*"test" + 0.031*"long" + 0.027*"diagnos" + 0.025*"stop" + 0.025*"****" + 0.023*"famili"

8. Forum 2 Emotionality Topic Model Distribution

1	0.014*"support" + 0.012*"mastectomi" + 0.012*"breast" + 0.011*"node" + 0.010*"nod" + 0.010*"lymph" + 0.009*"surgeri" + 0.008*"diagnos" + 0.008*"reconstruct" + 0.008*"group"
2	0.006*"jowel" + 0.005*"shefgirl" + 0.005*"recommend" + 0.005*"right" + 0.005*"major" + 0.004*"panic" + 0.004*"believ" + 0.004*"park" + 0.004*"book" + 0.004*"appreci"
3	0.006*"guess" + 0.006*"step" + 0.006*"distanc" + 0.005*"dont" + 0.004*"carboplatin" + 0.004*"young" + 0.004*"learn" + 0.003*"famili" + 0.003*"say" + 0.003*"ignor"
4	0.004*"work" + 0.004*"treatment" + 0.004*"start" + 0.004*"help" + 0.004*"today" + 0.004*"hair" + 0.004*"need" + 0.004*"better" + 0.004*"year" + 0.004*"day"
5	0.024*"https" + 0.016*"*************" + 0.013*"inform" + 0.012*"forum" + 0.012*"chemotherapi" + 0.012*"help" + 0.012*"litr" + 0.011*"guid" + 0.011*"http" + 0.010*"aim"
6	0.007*"wonder" + 0.006*"idea" + 0.006*"see" + 0.005*"answer" + 0.005*"check" + 0.005*"choic" + 0.005*"rosi" + 0.004*"pop" + 0.004*"ladi" + 0.004*"have"

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