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Revisiting agency and medical health technology: actor network theory and breast cancer survivors' perspectives on an adherence tool

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Abstract

Purpose Optimal treatment adherence is critical in the management of breast cancer patients/survivors taking hormonal therapy. However, lack of adherence is common. Many technologies have been developed to encourage medication intake, such as reminders on phones or digital pills, with varying degrees of success.

Methods To explore the role of technology in medical adherence requires a framework that considers all complexities of technology, from software to the end user's beliefs. Actor Network Theory (ANT) defines technology based on its technical, social, and abstract components. We conducted three focus groups, which we analyzed using a thematic analysis to determine topics in breast cancer survivors' discussions of these technologies. We also conducted a deductive content analysis using ANT concepts as codes.

Results In discussing the use of technology to improve medical adherence, participants had an empowering view of technology (48.8%) a neutral one (41.5%) or a disempowering view (9.8%). When it comes to their medication adherence, breast cancer survivors taking hormonal therapy perceived technology as something on which they could assert agency while their own agency dictated their adherence behaviors.

Conclusions In line with a non-technologically deterministic view of medical technologies, this finding shows that technology can be both constraining and enabling, depending on the specific context of human use. This networked understanding of technology in terms of social dynamics has relevant implications in designing interventions that use technology to improve adherence.

Keywords Medical Technology · Breast Cancer · Actor Network Theory · Adherence · Hormonal therapy

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1 Introduction

Medical adherence is the extent to which a patient's behavior follows medical recommendations [1–3]. Most commonly, adherence refers to patients' compliance with prescribed medication regimens [4–6]. Optimal treatment adherence is critical in the management of chronic diseases and has been associated with better clinical outcomes [7]. Unfortunately, low adherence to prescribed regimens is common [8–11] and can lead to worse health outcomes [12, 13], higher disease recurrence and rehospitalization rates [13], and higher healthcare costs [14–16]. In the last few decades, technology has been utilized to address issues of medication adherence. For example, multi-dose blister packs have been used to portion out and dispense various medications in an easy-to-use way. This allows patients to organize their complex medication regimens safely and conveniently [17]. Text messages using mobile devices have also been an efficient tool

to remind patients to take medications in various contexts and across different illnesses [18]. There are also various applications designed to help users remember and track their medication usage (e.g., the MedSnap ID app[1]). This relationship between technology and patient agency has implications that go beyond medical adherence and affects other aspects of our lives, especially in the current public health crisis of COVID-19.

Despite the advances in tracking medical adherence, these methods have relied on external indicators and measurements of compliance and adherence, which are prone to miscalculations. Medication adherence tracking technology has been developed with strategies and devices that are less reliant on patients' self-reporting to reduce patients' unconscious (e.g., as they can forget) or conscious misreporting (e.g., avoid disclosing non-adherence to their doctors to avoid being scolded) of adherence. Measures like pill counting and reviewing pharmacy records rely on patients' behavior (and not on self-reporting), which can be unreliable if patients use different or various pharmacies. Since patients may forget or do not disclose their untaken doses [19], pill counting and medication refill also do not directly reflect actual medication uptake [20, 21]. Moreover, observing medication intake risks that a patient can pretend to swallow their medication [22].

To address these issues with external (of the body) measurements, Proteus Discover developed a novel tool that tracks and measures adherence through internal (from inside the body) measurement and verification. It consists of an ingestible sensor, a wearable sensor patch, a mobile device application, and a provider portal [23]. Once the edible sensor is attached to the medication and the pill is ingested, the sensor interacts with stomach acids and sends a signal to the patch that records time of ingestion and basic biometric data, such as blood pressure. The information is sent to the mobile device application. Clinical studies show an overall accuracy of 97.6% in capturing compliance rates. The signal indicates the extent to which patients are following their medication regimen [24]. Studies also have shown that Proteus Discover helped providers determine which hypertensive patients need adherence counselling [25], facilitated timely intervention for patients with Hepatitis C infected patients [26], and captured positive detection accuracy of medication ingestion comparable to direct observation [27]. A recent study based on 10 semi-structured interviews with providers to explore how they view the potential role of Proteus Discover in their

patients' medication regimens showed that providers see Proteus Discover's potential benefit in tracking adherence to hormonal therapy in cancer survivors [28]. The reason we focus on Proteus Discover as a medical adherence technology is because of its novel (involving medication tracking through ingestion), its FDA approval, and its manufacturer's claim of solving many issues around medical adherence.

To explore medical adherence technologies like Proteus Discover, a comprehensive theoretical framework that considers all the social and technical parts of complex technologies must be used. Actor Network Theory (ANT; [29, 30] defines technological entities not just based on tangible components but also based on social and abstract components. All these entities interact and affect one another [31]. This networked view of technology critiques the Foucauldian deterministic view of technology by arguing that users' agency is not automatically challenged by an imposing technology but, rather, inherently dispersed. Because of this dispersed agency, technology also does not necessarily automatically empower the user to monitor or change their behavior and instead could be rejected, ignored, or overpowered by a user [32]. The actors that comprise a technology affect each other in a dynamic that a.) empowers, b.) takes agency away, or c.) does neither. ANT considers all the actors that comprise the complex network of what constitutes a medical technology—from patient users to doctors and researchers in a study.

In this paper, we apply our theoretical arguments to qualitative data we have collected from three focus groups of a diverse group of women diagnosed with hormonal receptor positive (HR +) breast cancer. One in eight women will have breast cancer in their lifetime, making it the most diagnosed cancer in women [33, 34]. Two-thirds of breast cancer cases are HR +, which means that their cancer responds to hormone therapy [35]. Hormone therapy reduces recurrence of breast cancer and mortality rates [13]. Despite these benefits, research has shown that breast cancer patients have poor medical adherence rates, ranging from 10–50% [9–11]. Our first research question is, how can ANT be applied to understand women cancer survivors' experience? How can breast cancer be defined by actors in both agentive and agentless ways to help us understand women's breast cancer diagnosis, treatment, and decisions about adherence to hormone therapy? To understand women's view of technology as an agent of compliance, our second research question is, what are women's perceptions of Proteus Discover (and other technologies)?

This paper will first go through the methods we used for data collection and outline our analytical approach and methods. Then, it will present the results of our ANT analysis, by first presenting how agency emerged in the experiences of women with breast cancer, then secondly, by showing the role of technology in discussions of medical adherence

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[1] A smartphone-enabled application that allows a user to take photos of their various pills to help determine any adverse interaction and track medication history: https://www.medsnap.com/press-room/medsnap-to-demonstrate-m-health-application-and-tool-that-improves-accuracy-of-medication-history/

more specifically. The discussion will then cover how breast cancer experiences were characterized by participants using the framework of ANT and how adherence technology was discussed in empowering, deterministic, or neutral ways.

2 Methods

2.1 Data collection

In a wider study aimed at exploring the experiences, behaviors, and motivations of women with breast cancer taking hormonal therapy, we conducted three focus groups. The eligibility criteria included anyone that was a woman over the age of 18 that was diagnosed with HR + breast cancer and started taking hormonal therapy – this included women who are in the extended and permanent survivorship part of the cancer survivorship continuum. Recruitment took place between August 2014 and August 2015. Flyers were distributed with the help of community organizations such as Pink Divas in the Washington DC metro area. The focus groups were conducted by playing an explanatory video about Proteus Discover and asking a group of women open-ended questions first about their experiences with breast cancer, treatment, survivorship and about their challenges and experiences with adherence to hormonal therapy. Then more specific questions about Proteus Discover and adherence technologies were asked based on the informational video we showed. We obtained ethical approval from the [anonymized] University IRB. Each focus group lasted between 1.5 and 2 h. The focus groups were conducted on March, August, and October of 2015. There was a total of 21 women that attended the focus groups with one focus group containing 5, another 8, and finally the third 8. One focus group comprised white women and two focus groups comprised exclusively black women, with all women being HR + and having initiated or completed hormonal therapy (see Table 1 for demographic information of the participants). Focus groups were recorded and transcribed.

2.2 Analytical approach

There were two phases of analysis (Figs. 1 and 2). First, each of the focus group datasets were randomly assigned to be reviewed by one of three authors to conduct a bottom-up analysis (Fig. 1). This process involved the identification of the various micro and macro components that comprise a technology according to ANT. We categorized these components as the medical, technical, social, personal, and external factors and components that emerged as themes within the data (see Fig. 3 for our ANT framework). Since the aim of this research was to use ANT, the coders specifically foregrounded entities mentioned in the dataset that were

Table 1 Demographic information for study participants

Demographics	count (%)
Race	
White/Caucasian	4 (19.0%)
Black/ African American	11 (52.4%)
Missing	6 (28.6%)
Ethnicity	
Non-Hispanic	15 (71.4%)
Hispanic	0 (0%)
Missing	6 (28.6%)
Marital Status	
Single	6 (28.6%)
Married/Living with Partner	4 (19.0%)
Divorced	6 (28.6%)
Widowed	1 (4.8%)
Missing	4 (19.0%)
Education	
≤ High School	4 (19.0%)
University (≤ 4 years)	8 (38.1%)
University (≥ 4 years)	5 (23.8%)
Missing	4 (19.0%)
Employment	
Working (full time)	9 (42.9%)
Working (part time)	1 (4.8%)
Retired	4 (19.0%)
Unemployed (health reasons)	1 (4.8%)
Missing	6 (28.6%)
Annual Income	
Less than $10,000	2 (9.5%)
$40,000–59,999	2 (9.5%)
$60,000–84,999	5 (23.8%)
$85,000–99,000	1 (4.8%)
$100,000–149,000	1 (4.8%)
$150,000–199,000	2 (9.5%)
$200,000 or more	2 (9.5%)
Missing	6 (28.6%)
Diagnosis Stage	
0	1 (4.8%)
1	3 (14.3%)
2	7 (33.3%)
3	3 (14.3%)
Missing	7 (33.3%)
Taking Hormonal Medication	
Yes	12 (57.1%)
No	2 (9.5%)
Missing	7 (33.3%)

'agents,' which we defined, in line with ANT, as any entity that affects another entity in some way. The coders also foregrounded the 'affected' entities mentioned in the dataset, which we defined as the entities that were affected by

Fig. 1 Phase I of data analysis
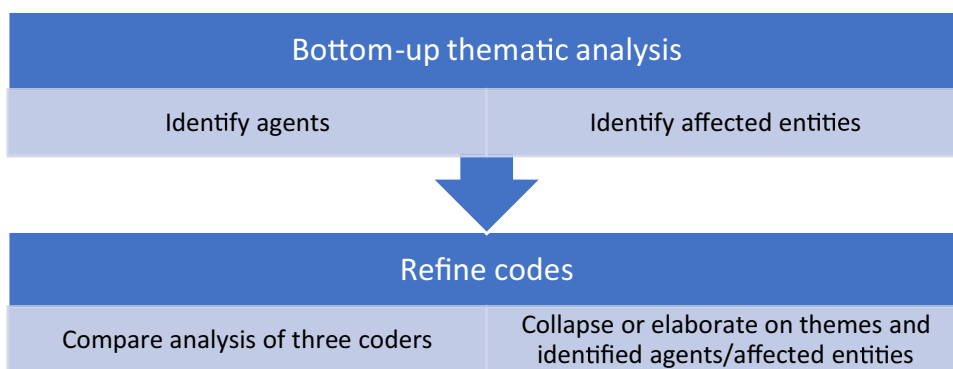
these agents. In other words, agents are entities that act and whoever or whatever these actions impact are the affected entities. For instance, this is a direct quote from our data: 'I mean then (my doctor) made me come back to his office some time in November.' The agent entity here would be the provider and the affected entity would be the patient participant of our study because the provider affected the participant's action of coming back to the provider's office. Then, we shared the results of their agent and affected entity analysis, discussing which entities were similar and different. Through this process, many themes were collapsed together or deleted depending on whether the themes were applicable to the rest of the dataset (three focus groups). The authors used the refined codes to independently code the entire dataset. When there was disagreement, the authors would discuss the meaning of codes and the links to the dataset, further refining the codes. As each code was refined, the authors would use them to code the entire dataset from the beginning again, in an iterative process.

The second phase of analysis explored women's perceptions of Proteus Discover along with other adherence technologies that emerged in the dataset (Fig. 2). First, we identified the technologies that women mentioned when discussing adherence. Then, we shared the technologies discussed in each focus group and defined technology categories that could be used to code the entire dataset. Finally, to apply the

ANT framework to the role that technology plays in adherence, we coded each sentence referring to technology based on the perspective of the participant. Namely, these sentences were coded as having a deterministic, empowering, or neutral perspective. For both the ANT and Proteus Discover analyses, we then calculated the percentage that each entity was an agent or affected entity or the percentage that each technology was discussed in deterministic, empowering, or neutral terms. For example, in the case of the participant being an agent, the percentage was calculated by dividing the number of times the participant was an agent by the total number of times any themes were used as agents. Salience of content in the dataset was gauged through how many times a theme or a perspective was used to code the data, in line with established methods of thematic analysis [36].

2.3 Data analysis

The aim of the analysis is to determine which themes are most salient in female cancer survivors' experience and which perspective of technology (deterministic, empowering, or neutral) is most prevalent in their perception of Proteus Discover. First, the three focus groups were assigned to three authors, who each independently coded the entirety of all three focus groups for the different experiences (e.g., with diagnosis, treatment) during women's time with breast
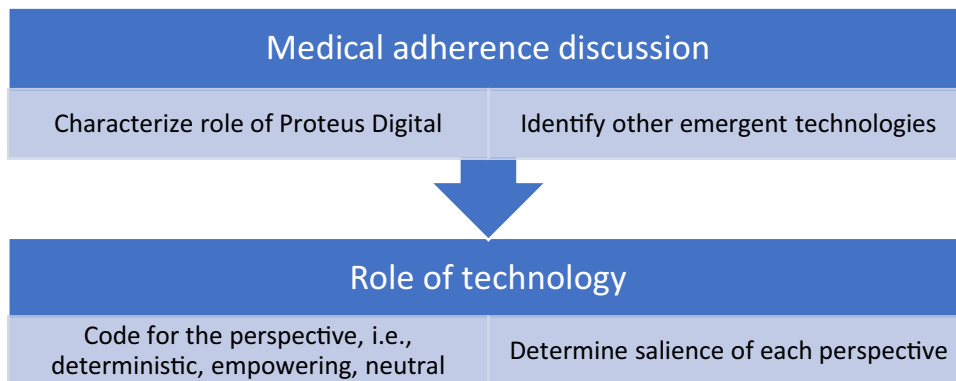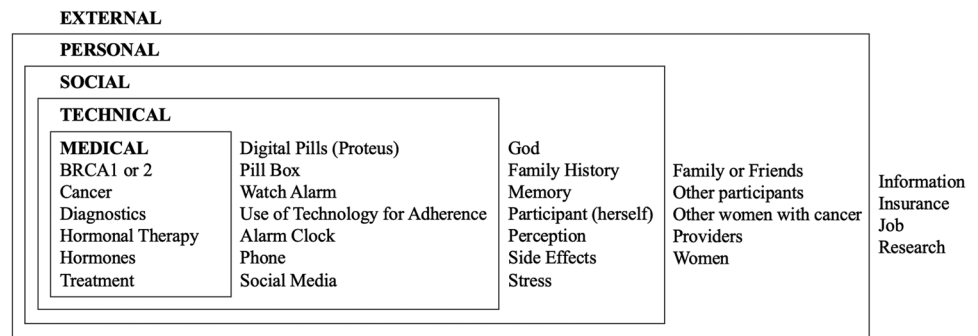
Fig. 2 Phase II of data analysis

Fig. 3 Actor Network Theory's sociotechnical view of medical technology

EXTERNAL				
PERSONAL				
SOCIAL				
TECHNICAL				
MEDICAL	Digital Pills (Proteus)	God	Family or Friends	Information
BRCA1 or 2	Pill Box	Family History	Other participants	Insurance
Cancer	Watch Alarm	Memory	Other women with cancer	Job
Diagnostics	Use of Technology for Adherence	Participant (herself)	Providers	Research
Hormonal Therapy	Alarm Clock	Perception	Women	
Hormones	Phone	Side Effects		
Treatment	Social Media	Stress		

cancer. The focus groups were coded using an inductive thematic analysis, based on principles borrowed from the grounded theory approach [37–40]. An inductive thematic analysis identifies content that emerges from the data from the bottom-up.[2] This approach was appropriate in this context as it allowed for stages to emerge in a data-driven way, without making assumptions regarding participants' experiences with breast cancer. The thematic analysis process was iterative and involved authors re-analyzing the entire focus group each time a new stage emerged and after considering the themes that emerged in other focus groups. After determining the stages of the breast cancer experience, we used a deductive approach based on ANT concepts to code the focus groups. The focus groups were coded for agentive and affected entities (for resulting codes, see Table 2). We called people and things in the discourse that were framed as exerting power and performing actions 'agents.' We called people and things that were recipients or receivers of those actions 'affected,' since they were affected in some way by the agentive actors' actions. These labels were based on the thematic analysis we conducted and allowed for the coding to reflect the concepts of the ANT theoretical framework, which foregrounds how different entities affect one another to comprise a network. Finally, the authors used the NVivo (version 12) software to examine the relationship between the entities in the dataset and explore the relationship between agents and affected entities and the nature of the patient's perspective of the use of medical technology.

3 Results

3.1 Agency during the experiences of women with breast cancer

When the participants spoke about their experiences with breast cancer, they brought up a network of entities that constructed their experience. Figure 4 shows the phases of women's breast cancer experiences and the issues around breast cancer that the participants mentioned. Participants discussed their diagnosis, which covers 6.2% of the entire dataset,[3] side effects of treatment (13.5%), and the coping mechanisms for dealing with breast cancer (5.8%). Taking up the largest chunk with approximately a third of the dataset, participants talked about their treatment (15.2%) and adherence to hormonal therapy (15.4%). The relationship built by the network of entities constituted the dynamics that characterize a participant's experience with breast cancer. The participants identified entities that were actors exerting agency or entities that were affected by those actors. Table 2 shows the most salient agents and affected entities that the participants in our study identified. Within the breast cancer experiences, the most salient agents that emerged in the focus groups were the participants themselves (22.4%), healthcare providers (15.9%), hormonal therapy (12.4%), God (8.1%), and treatment (7.3%). Other agents included BRCA1/2 gene mutation, breast cancer, diagnostics, family history, family/friends, hormones, information, insurance, job, memory, other participants, other participants with breast cancer, perceptions, side effects, stress, technology, and women in general. The most salient entities that were affected by agents were the participants (56.1%), treatment (18.3%), side effects and breast cancer (4.3%), and providers and hormonal therapy (4%). Other affected agents mentioned include family/friends, perceptions, diagnostics, women in general, hormones, and memory.

3.1.1 Breast cancer diagnosis

When participants discussed diagnosis, providers were the most salient agents (30.5%) as they were agents almost a third of the time (see Table 3). Participants themselves were agents 22% of the time, followed by God (13.6%), stress (9.8%), and family and friends (8.5%). In terms of

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[2] A deductive approach in contrast is when a pre-existing set of codes are used on a dataset to find how many times that dataset contains those codes.

[3] The percentages of the dataset reported means the percentage that a theme was utilized.

Table 2 The agents and affected entities in women's breast cancer experiences

Agents in Breast Cancer Experience		Affected entities in Breast Cancer Experience	
Participant	83 (22.4%)	Participant	208 (56.1%)
Providers	59 (15.9%)	Treatment	68 (18.3%)
Hormonal Therapy	46 (12.4%)	Cancer	16 (4.3%)
God	30 (8.1%)	Side Effects	16 (4.3%)
Treatment	27 (7.3%)	Providers	15 (4.0%)
Family or Friends	22 (5.9%)	Hormonal Therapy	15 (4.0%)
Cancer	18 (4.9%)	Other women with cancer	10 (2.7%)
Information	16 (4.3%)	Perception	9 (2.4%)
Research	10 (2.7%)	Family or Friends	8 (2.2%)
Technology	8 (2.2%)	Women	2 (0.54%)
Side Effects	7 (1.9%)	Diagnostics	2 (0.54%)
Insurance	7 (1.9%)	Hormones	1 (0.27%)
Other women with cancer	6 (1.6%)	Memory	1 (0.27%)
Perception	5 (1.3%)	God	0
Stress	5 (1.3%)	BRCA1 or 2	0
Memory	4 (1.1%)	Information	0
Family History	4 (1.1%)	Research	0
Job	4 (1.1%)	Technology	0
Hormones	3 (0.81%)	Insurance	0
Women	2 (0.54%)	Stress	0
Diagnostics	2 (0.54%)	Family History	0
BRCA1 or 2	2 (0.54%)	Job	0
Other participants	1 (0.27%)	Other participants	0

Data is represented by number of clauses and (percentages)

the affected entities, the most salient were the participants themselves (62.7%), breast cancer (13.6%), healthcare providers and treatment (8.5%), and diagnostics (3.4%). One participant mentioned how stress affected her by causing breast cancer, which shows how stress is an agent and breast cancer an affected entity:

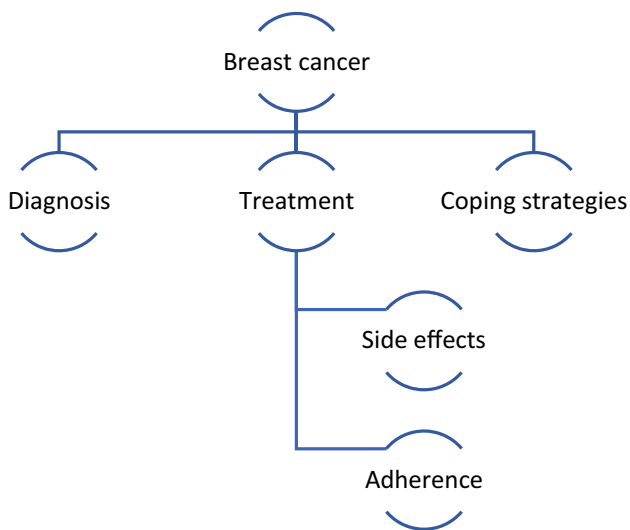> *But I think my job caused my breast cancer because it was so stressful.*

3.1.2 Breast cancer treatment

As participants then talked about their treatment, approximately a quarter of the times, the providers are the agent (20.8%), followed by participants (19.2%), information (9.6%), breast cancer and treatment (6.4%) (see Table 3). Technology appeared as an entity here and is the agent 3.2% of the time. Participants were the affected entities 48% of the time, followed by treatment (29.6%), breast cancer and hormonal therapy (4.8%), and other women with cancer (3.2%). For instance, one participant's choice for treatment depended on information:

> *I went to the American Cancer Society because I thought I would narrow it down and then I went in with some terminology at least so I could talk intelligently about it or know what someone was telling me.*

Fig. 4 Women's breast cancer experiences

Table 3 Most common agents in specific stages of breast cancer experiences

Diagnosis	Treatment	Coping Strategies	Side Effects	Adherence
Providers (30.5%)	Providers (20.8%)	God(17.9%)	Participants (23.8%)	Participants (34.8%)
Participants (22.0%)	Participants (19.2%)	Participants (17.9%)	Hormonal Therapy (23.8%)	Providers (21.7%)
God(13.6%)	Information (9.6%)	Hormonal Therapy (15.5%)	Treatrnent (11.4%)	Technology (17.4%)
Family (8.5%)	Treatment (6.4%)	Providers (11.9%)	Providers (9.8%)	Family (17.4%)
Stress (8.5%)	Cancer (6.4%)	Treatment (9.5%)	God (5.7%)	Other women with cancer (4.4%) Cancer (4.4%)
		Family (9.5%)		

3.1.3 Breast cancer coping strategies

The participants also discussed the coping strategies they employed when dealing with breast cancer (see Table 3). When participants talked about coping strategies, God and participants are the agents 17.9% of the time, followed by hormonal therapy (15.5%), providers (11.9%), and family and friends and treatment (9.5%). In terms of the affected, the most salient entities were the participants themselves (67.9%), followed by treatment (9.5%), other cancer survivors and perceptions (6%), and side effects and hormonal therapy (3.6%). One participant described how she:

> …had a lot of fear, but cancer turned me around because I changed that fear into faith and God had his hands on me.

3.1.4 Treatment side effects

As participants then talked about the side effects of their treatment, approximately a quarter of the time, hormonal therapy and participants were the agents (23.8%), followed by treatment (11.4%), providers (9.8%), and God (5.7%) (see Table 3). One participant described the side effects of Aromasin, a hormonal therapy:

> And then I went on Aromasin after two and a half years and there are enormous side effects. You couldn't get out of the car without every joint – your knees hurt, your hands hurt – I couldn't open jars. What other side effects? Dry eyes.

Participants were the affected entities 52.3% of the times, followed by treatment (15.5%), side effects (8.3%), hormonal therapy (7.8%), and perceptions (4.1%).

3.1.5 Treatment adherence

When participants brought up the topic of adherence, they themselves were the agents 34.8% of the times, followed by providers (21.7%), family and friends (17.4%), and cancer (4.4%) (see Table 3). Unique to the discussion of treatment is that technology was a salient agent (17.4%). One participant offered a potential technological solution for reminding to take hormonal therapy:

> I think that's when the technology comes in: for people who need an advocate and not only a family or friend. Having that put on you and then your advocate, which again, could be in India, a call center in India, would call you up and say "hey, have you taken your pill?", "Do you know where it is?" you know that could work. And that may be what some people want. It's close enough but not really personal. No judgment.

Participants were the affected entities more than half of the time (60.9%) followed by treatment (39.1%). Participants were mostly affected by providers, family and friends, and technology. One participant discussed how women with breast cancer, especially those who may lack medical knowledge, could potentially improve their adherence to medication if they had a professional to talk to when they first get diagnosed with breast cancer:

> But if somebody is not college educated or in the medical profession, you know, maybe there's a disconnect there. So a psychologist or somebody to sit down with: "how are you?…you're supposed to go on this regimen – how's that going?" You'll learn more by talking to somebody.

Table 5 Specific technologies discussed by perspective in discussions of Proteus Digital

Technology	Empowering (critique of Foucault)	Neutral (women exerting agency)	Foucauldian (agency taken away)
Digital Pills (Proteus)	9 (47.4%)	2 (10.5%)	8 (42.1%)
Pill Box	6 (85.7%)	0	1 (14.3%)
Watch alarm (e.g., fitbit)	2 (40.0%)	0	3 (60.0%)
Use of technology for adherence	1 (25.0%)	1 (25.0%)	2 (50.0%)
Alarm clock	2 (100.0%)	0	0
Phone	0	1 (50%)	1 (50.0%)
Social media	0	0	2 (100.0%)

Data is represented by number of clauses and (percentages)

Table 4 Technologies discussed by perspective and salience

Technology	Empowering (critique of Foucault)	Neutral (women exerting agency)	Foucauldian (agency taken away)	Total overall
Digital Pills (Proteus)	9 (45.0%)	8 (47.1%)	2 (50.0%)	19 (46.3%)
Pill Box	6 (30.0%)	1 (5.9%)	0	7 (17.1%)
Watch alarm (e.g., fitbit)	2 (10.0%)	3 (17.6%)	0	5 (12.2%)
Use of technology for adherence	1 (5.0%)	2 (11.8%)	1(25.0%)	4 (9.8%)
Alarm clock	2 (10.0%)	0	0	2 (4.9%)
Phone	0	1 (5.9%)	1 (25.0%)	2 (4.9%)
Social media	0	2 (11.8%)	0	2 (4.9%)
Total by perspective	20 (48.8%)	17 (41.5%)	4 (9.8%)	41

Data is represented by number of clauses and (percentages). The 'total overall' column represents the amount of time that specific technologies were discussed while the 'total by perspective' row represents the amount of time all technologies were discussed using a specific perspective

3.2 Technology in medical adherence: deterministic, empowering, and neutral

This section presents results from the analysis of the sections of the focus groups specifically asking about Proteus Discover, addressing our second research question regarding technology in medical adherence (Table 4). Although Proteus Discover was the center of attention in this portion of questions we asked during the latter part of the focus groups, the participants identified other technologies commonly used to improve treatment adherence, with many participants, for instance, bringing up other means to remind themselves to take hormonal therapy. Digital pills were the main technology discussed (46.3%) followed by pill boxes (17.1%) and watch alarms such as Fitbits (12.2%). For example, one participant discusses how she would use the Proteus Discover:

> *I would use this for seeing how the pills affect my blood pressure. If it records stuff like my blood sugar – if that's what it can do*

In discussing the use of technology to improve medical adherence, participants tended to have an empowering view of technology (48.8%) or a neutral view (41.5%) as opposed to a Foucauldian view (9.8%) (Table 4). The finding that participants had a more empowering or neutral view of technology was consistent in discussing all types of technologies. In evaluating the Proteus Discover, participants also tended to have an empowering view of technology (47.4%) or a neutral view (42.1%) over a Foucauldian view (10.5%) (Table 5). The consistency of this finding was somewhat expected as we specifically asked about Proteus Discover, also making it the most discussed technology. An example of a participant adopting an empowering view is the following, when the participant discussed why she uses her phone as a reminder:

> *When I first started out, because I took it (hormonal therapy) at night, I had to remind myself. So at 10 o'clock every night, my phone makes a buzz. My girlfriend was like, well what is that? Well that's to remind me to take my pill.*

4 Discussion

Study findings suggest that participants perceived technologies as empowering them and most importantly as something that they themselves can overpower. This next section discusses the implications of this finding, linking the results to theoretical ramifications of medical device technologies on patient agency, the problem of medical adherence, and to the design of social support interventions using technology.

4.1 The networked breast cancer experience

The findings show how participants characterized their breast cancer experiences as a network of technological and social entities imbued with agency to affect other entities (see Fig. 3 for all socio-technical aspects emergent in the data). Exemplifying the networked nature of the agency in women's breast cancer experiences is the finding in our study of several non-human agents. At least two non-human agents are part of the most common five entities in all breast cancer experience stages, suggesting that non-human agents (i.e., God, stress, information, treatment, cancer, hormonal therapy, and technology) are salient entities in throughout the breast cancer experiences of diagnosis, treatment, coping, side effects, and adherence to hormonal therapy (Table 3). The reason behind this can be partially attributed to the fact that participants were asked about cancer, hormonal therapy, etc. apart from God, as no question in the focused groups asked about God, religion, or faith.

The first agent that comes to the fore in the discourses of the participants is thus God not only because of its salience in multiple stages of the breast cancer experience but also because its presence was not directly prompted by our questions during the focus groups. When women discussed their experiences with breast cancer diagnosis, it makes temporal sense that providers would be the most salient agents and that participants would be the overwhelmingly most affected entity because it is during diagnosis that providers would do the diagnosing. For instance, when one participant said, 'I was diagnosed with breast cancer in 2013,' it must also be inferred that the agent that does the diagnosis is a healthcare provider, such as an oncologist. The entities of God, stress, and diagnostic tools become salient during participants' discussion of their diagnosis experiences. It is intuitive that diagnostic tools would become salient only when participants talked about their experiences with diagnosis. However, these findings also suggest that the diagnosis stage of their breast cancer experiences is when spirituality (i.e., God) is used by women to provide context of why they believe they were diagnosed with breast cancer. For instance, one participant said that 'God protects babes and boos' when she discussed how lucky she was when she was diagnosed early with breast cancer. This is consistent with studies on the role of religiosity and spirituality in finding meaning during illness [41]. In fact, God becomes the most salient agent when the participants described their breast cancer coping strategies. Here, women position themselves as four-fifths of the affected entities, which makes sense in the context of them being affected by the agent of God. One participant directly claimed that 'faith is what helps to sustain me.' In other words, a coping mechanism for the physical and psychological turmoil that comes with experiencing breast cancer is spirituality.

Another agent besides God that stands out in the discourse of the women is the agent of technology, which is the most common non-human agent in the adherence stage (Table 3). In the treatment experience, technology played a major role for many participants. For instance, one participant discussed how one must 'set a reminder on your iPhone' when having to take self-administered therapy such as pills. Many studies have shown the benefits of using digital technology to help with compliance and adherence [42]. For example, Sabin and colleagues [6] designed an intervention that electronically monitored adherence rates of patients taking antiretroviral therapy and provided them with automatic reminders to take medications through mobile phones. There was a significant increase in adherence to therapy [6]. That technology such as iPhone reminders and Fitbits are a part of participants' treatment experience shows how useful technology can be through its reminder function. Studies further suggest that technologically driven interventions focusing on monitoring therapy intake and/or providing information to patients may benefit from a digital-based reminder system [43]. Indeed, a meta-analysis of interventions and RCTs using mobile text messaging shows that they significantly improve therapy adherence rates in people with chronic disease [44].

More so than merely playing a role though, technology is also a definitive part of what treatment is to the participants in our study (Table 3). The iPhone in the example above altered the interactions between the patient and the treatment as the patient's abilities of recall are given to a technology and that technology, in turn, serves a reminder function on which the patient can act. Furthermore, unlike in our dataset as a whole, it was when participants spoke of adherence more specifically that they brought up technology (Table 3). Referring to the commonly used seven-day pill organizer, one participant discussed the importance of using it to take hormonal therapy daily and on time: 'without the box, I would never know. Because the box makes it mindless. And you take it the same time every day.' Another participant moreover suggested that it would be helpful if providers told patients to 'get the box,' referring to the seven-day pill organizer, to help them with taking their hormonal therapy. Medication intake is not merely the discrete action of a patient swallowing a pill, but a network comprised of human and non-human actors that influence each other in a specific context.

4.2 Medical adherence and proteus discover from an actor network theory perspective

Our findings that participants were mostly empowered by – or were neutral about – technology when it comes to their medication adherence has implications on the technological deterministic view of technology. Using Jeremy Bentham's account of 18th-mcentury prisons, Foucault and Bouchard [45] described the architectural design of a panopticon. The circular prison with cells on the perimeter facing the center, the panopticon enables one guard to keep his eye on all prisoners whilst also affording the effect of preventing prisoners from seeing that guard. The psychological consequence is that prisoners assume they are continually watched and as a result, self-sensor their behavior, even if they cannot really know if someone is watching. Thinkers like Holmes [46] argued that this sort of systemic domination manifests itself now, especially through modern medical technology. The medical establishment uses monitoring devices, for example, to intimately track a patient's vitals during surgery or treatment. These instruments only afford medical professionals to surveil patients and not vice versa. This unidirectional nature of patient-doctor surveillance renders the patient in a constant state of surveillance in which their agency is reduced [47, 48]. If agency is the ability to think and act freely [29, 30], medical technologies situate patients within power relations with machinery. This suggests that technology reduces human volition and autonomy within those relations, reducing and challenging patients' agency.

The main issue with this technological determinist view of medical technologies is that it ignores instances of when patients behave in ways that are agentive. For instance, many patients are observed as purposely pretending to take their medication when asked by their providers about their compliance to medication [49, 50]. This phenomenon shows that individuals may be more comfortable in feigning compliance than in sharing the genuine challenges they face in taking the medication. Adherence issues thus entail a power imbalance between doctors and patients that must consider other possible actors in the discourse about medical adherence besides technology.

From an ANT perspective, we cannot assume that technology would either function as social control mechanisms as the medical technology literature posits or that technologies such as Proteus Discover will readily result in increased social support. As we have argued in a previous theoretical paper about the methodological implications of ANT in the context of medical adherence [32], there is a need to conduct empirical studies that explore how Proteus Discover works in the social context of patients from different socioeconomic and ethnic/racial backgrounds and with different types of diseases. Challenging the technological determinist view of medical technologies, which attributes behavioral changes primarily to technology [51], the findings in this empirical study show that most participants perceive technology in an empowering way followed by a neutral way. This finding suggests that medical technologies, such as Proteus Discover, do not always reduce human independent capacity to act. Rather, the participants perceived Proteus Discover as an entity on which they could assert agency

while their own agency dictated their adherence behaviors. In line with a non-deterministic view of medical technologies, this finding shows that technology can be both constraining and enabling depending on the specific context of human use [52].

Another relevant finding in this context is that the neutral view of medical technology is also salient in the discourse regarding Proteus Discover. While the empowering view of medical technology is the most prominent, the difference between the empowering view (48.8%) and the neutral one (41.5%) is not as pronounced as the one between the empowering view and the Foucauldian one (9.8%). Coherent with the ANT perspective, this finding shows that using technology does not necessarily result in the clear-cut loss of agency or in outright empowerment. When agency is conceptualized as the capacity to make a difference on other actors' actions [30], patient agency in adhering to medication is not eliminated but dispersed within the human and non-human actors that comprise the patient's network and it becomes an object of study per se. These findings are also consistent with other studies, which show specialized care, having more prescription medication, and fewer hospitalizations were related to higher adherence [53]. Studies that looked at psychosocial predictors which are amenable to change show that, for example, medication beliefs [8], spirituality [41], and self-efficacy [54] are also factors that are related to adherence rates. With the current framework of patient-centered medical practice, efficient communication is viewed as a cornerstone of optimal care [55]. Technology can be seen as a tool aiding all stakeholders, from practitioners to patients, to communicate better and to ultimately ensure better therapy adherence [56].

ANT also offers a way to view the complications of patient adherence behaviors. ANT is a conceptual framework that defines agency as dispersed because its unit of analysis is networks, which is a relationship between entities whose agency is dependent on the network itself [57]. Because the only requirement for an entity to contain agency is being part of a network, an entity can be human, material, and abstract [29, 58, 59]. Goodwin [60] applies ANT on a description of patients undergoing anesthesia and their gradual loss of physical and mental facilities to sustain their own life. Agency is dispersed through the network of the anesthesiologist, the various hemodynamic machine monitors and organ diagnostic machines, and medical protocol. Where Foucault and Bouchard [45] theorize power as part of a constellation of resistances in which technology is a mode of controlling people, Goodwin [60] theorizes agency as situated within the sociotechnical arrangements that comprise a network in which technology is not inherently value laden. In short, ANT allowed us to inquire about how social functions are being performed within a complex network of diverse actors. For characterizing the complexities of adherence behaviors within the context of medical adherence tools, ANT offers analytic leverage because its conceptual framework allows social phenomenon to enmesh the human, the material, and the technological in a way that threats them and uses their relationships as the unit of analysis.

4.3 Implications

The pandemic has left many—especially non-essential workers that do not experience symptoms but want to consult with their doctors—to utilize technology as a mediator of communications. Due to the attempt to minimize physical interaction but also track people's potential COVID-19 symptoms, many non-essential workers are also asked to keep track of their symptoms through apps, such as the COVID Symptom Study app in the UK.[4] One main way that governments are mitigating the spread of the novel coronavirus is through mandatory contact tracing, which, for example, requires that people provide their contact information to restaurants, or requires that people that test positive for the virus to provide the information of those they have been in contact with. On top of the issue of the wider public having to weigh personal liberty and public health measures, one main issue with such measures is that they rely on the complex relationship between individuals' personal agency and the role of technology. For instance, social distancing, quarantine, and lockdown policies that have been implemented all over the world have rendered much social interaction mediated by phones and computers. People are rendered reliant on such technologies to conduct business as usual in the new normal. What potential effects does this have on individual agency, especially when measures are meant to ease public health but at the detriment to many personal freedoms?

4.4 Limitations

Despite ANT's insight into agency and the issues with technological determinism, it is not to say that ANT's arguments are unproblematic. The theoretical issues with ANT have to do with its vast definitions and seemingly universal applicability. If agency is dispersed in the manner that ANT conceptualizes, that is by extending agency to the conceptual, and abstract as well as to the material, where does agency *not* lie? If an entity is to be defined in accordance with ANT, with all its networked components considered, where exactly does

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[4] For more information about this application, see: https://play.google.com/store/apps/details?id=com.joinzoe.covid_zoe&gl=US

the network end and why? Furthermore, what is the threshold for how much salient difference an agent has when defining its detectable effect on another agent? While such criticisms have significant implications in the way ANT can be used as a theoretical lens, they do not hamper the insights and plethora of questions that medical technologies beg. What ANT does is suggest other ways to view and discuss technology's involvement in sickness and healing in such a way that deconstructs commonly held views. Despite these possible limitations, ANT still offers a way of discussing and exploring the same subject of past inquiries regarding technology and society and has implications for medical adherence.

4.5 Future lines of research

Using ANT to frame medical adherence technology affords us to consider avenues yet to be explored, especially as devices like wearable fitness trackers and health apps have seen increasing popularity. Empirical studies exploring how users communicate about using such devices would benefit from utilising ANT. For some individuals, having a friend remind them to take a pill or to walk more steps can be a sign of support, whereas for others, such nudges can be construed as overly invasive. The way the reminder is construed relies on the type of relationship with the friend, tone of the message, etc. Such a social interaction, more common now with wearable devices and smart technology, can potentially lead to conflict or hiding certain behaviors. Clinician-patient communication about medication intake could influence the patient's perception of the social support they are receiving from their providers. Adherence technologies could be seen as something that benefits their support and care or, on the other hand, they could be perceived as a tool to control the patient and breach their privacy. Rather than assuming one of these perspectives over the other, ANT necessitates considering the specific context and circumstances. Any information about a patient's medication intake or behavior could be a chance to also elicit and better understand their values, challenges, preferences, and health goals. To conduct such exploratory studies, it is important to consider the necessary issues inherent in health-related technologies. They may seem to be a mere means by which people can be reminded to take medication or track the amount of activity they expend in a day. However, this implies that individuals act as the only agent in a system where their utilization of the technology is the defining action of that technology. Such a linear relationship overlooks everything else that affects the medical technology and what the technology itself affects, which can lead to overly restrictive hypotheses and biased analyses that do not account for the complexities inherent in the technology. Future research can further examine other health apps using the ANT framework to address these important gaps in the literature.

The participants in our study were either taking the hormonal therapy or had completed treatment. Future lines of research can examine the perceptions of medical adherence technology in breast cancer survivors who discontinued treatment, particularly exploring the role of such technologies in their reasons behind discontinuation. Furthermore, we did not consider the sociodemographic features of our participants (see Table 1) despite that features like socioeconomic status and race often play a role in adherence behaviors. Future inquiry can use ANT to expand on the current literature on adherence behaviors in diverse populations. Health-related technology is often portrayed as perpetuating the notion that individuals aim for optimal health and wellbeing but often forget or intentionally skip medication. Assumptions like this are thus also involved. Conceptual issues such as socio-economic status, cultural affinities, and politics may play a role. Does the agentive nature of a health technology lie solely in its potential to be part of a mechanism that affects behavior only once an agentive patient decides to use it? Or does its agency potentially also lie in the full array of its potential benefits once it is used? Viewing into the Blackbox of health technologies using the concept of dispersed agency exemplifies how ANT is useful in addressing many of these significant questions. When exploring any medical technology, it can be useful to view it as more than just a technical artifact but as a network of technical, organizational, and social actors.

5 Conclusion

Utilizing the ANT framework, the study's first finding is that participants characterized their breast cancer experiences as a network of technological and social entities imbued with agency to affect other entities. Coherent with the ANT perspective, this finding shows that using technology does not always result in a clear-cut loss of agency or in outright empowerment. Rather, when agency is conceptualized as the capacity to make a difference on other actors' actions, patient agency is dispersed within the human and non-human actors that comprise the patient's network. Actors thus affect or are affected by each other in such a way that comprises and results in the experiences of the women's breast cancer diagnosis, treatment, and decisions regarding adherence to hormone therapy. Notably, there are several different agents that interact and affect each other during the different stages of women's cancer experiences. Given this dispersed agency framework, our second finding is that technology does not automatically empower its users, function as social control mechanisms, or improve adherence behaviors. Most participants in this study perceived technology in an empowering or a neutral way, suggesting that the medical technologies do not always reduce human independent capacity to act. Rather, technologies are perceived as entities on which patients assert

agency while their own agency dictates their adherence behaviors. In line with a non-deterministic view of medical technologies, this finding shows that patients conceptualize technology differently and diversely, based on the specific contexts of use. Challenging the technological determinist view of medical technologies, this study shows that the ANT framework affords an insight into the nature of complex relationships between actors involved in this phenomenon. A better understanding of such dynamics can have relevant implications in designing interventions that use technology to improve adherence behaviors.

Declarations

Ethics approval statement This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Institutional Review Board at Georgetown University.

Consent to participate statement Informed consent was obtained from all individual participants included in the study.

Consent for publication Patients signed informed consent regarding publishing their data.

Conflict of interest The authors have no relevant financial or nonfinancial interests to disclose.

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