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The Power of the Patient Voice: Learning Indicators of Treatment Adherence from an Online Breast Cancer Forum

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Abstract

Social media platforms have become popular online environments for patients seeking and sharing treatment experiences. These platforms enable us to move beyond traditional sources of clinical information for learning about a patient's long-term adherence to treatment. While adherence has been studied using data derived from medical records and structured surveys, these approaches are limited in that they are often 1) time consuming, 2) limited in scale, or 3) lack self-reported patient experiences. In this paper, we investigate treatment adherence through a patient's self-reported information in online discussion forums. Specifically, we consider hormonal therapy treatment adherence (HTA) for hormone receptor positive breast cancer, a disease subtype that comprises 75% of all breast cancer cases. We focus on the inferred emotions and personality traits from the posts created by the members of a large online breast cancer community. These factors have been neglected in traditional adherence research due to a lack of information. We study over 130,000 posts from the forum, spanning 10,000 patients over 9 years. We assess emotion and personality traits with respect to three types of adherence behaviors: 1) currently on a regimen, 2) an interruption (due to discontinuing, pausing, or switching a medication regimen before five years) and 3) the completion of a five-year protocol. We find statistically significant differences in emotions across adherence behaviors. We further show that specific personality traits, including self-discipline, are associated with HTA, but in the opposite direction than what traditional research studies have shown. Finally, we illustrate that there is potential for predicting future interruption behaviors based on an individual's posts. We anticipate that our methodology can be applied to study treatment adherence for other diseases using online self-reported information.

Introduction

Social media platforms have received substantial attention from individuals who are seeking, or looking to share information about their treatment experiences. There are many online health communities that have been established, many of which have been in existence for over a decade, such as depressionforums.org and breastcancer.org. These environments are notable because it allows individuals to speak candidly and at length with others who have been diagnosed with similar problems. At same time, these online communities open up novel opportunities to learn about long-term adherence to treatment.

Ensuring adherence to long-term treatment protocols is crucial to improving survival rates for many health issues (e.g., cancer (Magai et al. 2007), diabetes (Ciechanowski et al. 2001), and sexually-transmitted diseases like HIV (Gonzalez et al. 2004)). For example, hormonal therapy is a proven treatment known to boost the survival rate of breast cancer patients (Murphy et al. 2012), but the benefits are maximized when patients are on the protocol for at least five years (Gotay and Dunn 2011). However, adherence to long-term treatment is challenging for many patients. For example, it is reported that only around half of patients who start a hormonal therapy regimen actually complete the five-year treatment (Chlebowski, Kim, and Haque 2014). There are numerous obvious reasons for lack of adherence, such as the cost of medication, adverse side effects, and the recurrence of disease during therapy. Still, other reasons are more subtle. For example, (Kuba et al. 2016) found that 14% of studied patients stopped treatment "for no particular reason". A deeper understanding of the factors associated with adherence is necessary if society aims to improve current adherence rates.

There have been various investigations into regimen adherence. However, a large portion of these investigations have relied on primary data collected through formal survey methodology (Bhatta et al. 2013; Wuensch et al. 2015; Beryl et al. 2017). Surveys are notable because they standardize and control the questions asked, but they are time-consuming and are often restricted to a limited number of participants. At the same time, investigations have focused on secondary data derived from electronic medical records (EMRs) and other traditional clinical resources (Wigertz et al. 2012; Makubate et al. 2013; Brito, Portela, and de Vasconcellos 2014). EMRs enable observational studies on large cohorts with a wide range of factors documented in the clinical setting (Tiro et al. 2015), but they often lack the voice of the patients themselves. Patient-reported outcomes, if collected, are usually structured (Basch et al. 2014) and unlikely to reveal nuances such as patients' emotions, feelings and experiences.

Thus, in this paper, we aim to demonstrate that treatment adherence can be studied in online health communities. Specifically, we focus on learning hormonal therapy adherence (HTA) from patients' self-reported information on the breastcancer.org online discussion board. Specifically, for the purposes of this investigation, we label HTA behaviors as three types of events: 1) *taking* - where a prescribed medication is consumed according to an oncologist's recommendation, 2) *interruption* - where the patient stops (or pauses) a regimen, or switches to a different medication (with or without clinician advice), and 3) *completion* - where a patient achieves the endpoint of a five-year treatment protocol. Given these types of events, we address three research questions: First, *To what extent are breast cancer patients' emotions correlated with different treatment decisions (**R1**)*? Second, *Are personality traits associated with HTA (**R2**)*? And, third, *Can we predict future interruptions based on the information posted by patients in online forums (**R3**)*?

To investigate these three research questions, we begin by extracting statements related to adherence events via a combination of rule-based filtering and statistically-informed classification models. Next, we apply a one-way ANOVA test on the emotion scores of sentences that mention adherence events. Then, we study the association between personality traits and two HTA groups (with completion events vs with interruption events) using logistic regression (LR) analysis. Finally, we build a LR model to examine the extent to which posts predict interruption events in future. The main contributions of this paper are summarized as follows:

- **Emotions**. We find that patients in online health communities tend to exhibit fear with taking events, anger with interruption events, and joy (with a tinge of sadness and disgust) with completion events.
- **Personalities**. We demonstrate that personality types, extracted from patient self-reported online information, confirm the majority findings in more traditional treatment adherence studies. At the same time, we show there is a discrepancy with a particular personality type, suggesting further opportunities for investigation.
- **Predictability**. Based on features derived from discussion posts, a classification model can obtain an area under receiver operating characteristic (ROC) curve (AUC) of ~ 0.8. The most informative features suggest that patients who are at the beginning of therapy and mention side effects (e.g., depression) are more likely to experience an interruption than those further into treatment.

Background and Motivation

In this section, we review how treatment adherence, with a focus on breast cancer, has been studied through traditional surveys, secondary EMR analysis, and (more recently) in online environments. We highlight the limitations of these studies, but also the main findings, which we use to guide our own investigations.

Factors Associated With HTA

Side effects are known to be important factors leading to low HTA (Kuba et al. 2016). At the same time, there are many other factors that associate with low HTA. For instance, Wu et al. (Wu and Lu 2013) showed that high healthcare costs are associated with suboptimal adherence. Neugut et al. (Neugut et al. 2016) observed that patients with nonadherence experiences for chronic diseases are less likely to adhere to hormonal therapy. It has also been suggested that patients with stage IV cancer, as opposed to earlier stages, are more likely to exhibit lower HTA (Brito, Portela, and de Vasconcellos 2014; Schmidt et al. 2014).

Personality traits have also been studied for their connections with treatment for numerous health issues (Christensen and Smith 1995; Stilley et al. 2004; O'Cleirigh et al. 2007; Bruce et al. 2010). Recently, Song et al. (Song et al. 2015) showed that breast cancer patients with a lower trust in their oncologist and a lesser ability to cope with potential hormonal therapy toxicity tend to have low HTA. However, these investigations are limited in scale and the intensive nature of survey design and collection make them cost prohibitive. To the best of our knowledge, ours is the first work to investigate the association between personality traits and HTA through *patients' self-reported information* in an online health community.

Various associations between negative habits and HTA have also been discovered. For instance, Brito et al. (Brito, Portela, and de Vasconcellos 2014) showed that patients who drink alcohol tend to have low HTA. There are some studies that have investigated the association between emotions and HTA. Generally, these studies have found that negative emotions are related with low HTA (Stanton, Petrie, and Partridge 2014; Walker et al. 2016). These studies are limited, however, in that they focus solely on interruption behaviors. Notably, we anticipate that significant factors will vary based on cohort characteristics and it is difficult to generalize across cohorts. Online social platforms, by contrast, may enable us to observe a potentially more diverse set of patients than may be included in studies where the cohort is carefully selected.

HTA Study on Social Media

Social media and online forums are increasingly relied upon to conduct health-related studies. These studies have a broad range, including flu trends (Vos and Buckner 2016; Yun et al. 2016), mental health (Brito, Portela, and de Vasconcellos 2014; Schmidt et al. 2014), extracting medical related languages (Elhadad et al. 2014), how to build online communities to provide local cancer support (Weiss 2009; Frost et al. 2012), and privacy issues associated with health mentions (Yin et al. 2015; 2016). Given the unstructured nature of the data source, researchers have started applying clustering or topic modeling to further standardize the concepts mentioned in online environments, thus providing better interpretations with the derived latent structures and emerging patterns such as symptoms and risk factors (Wang et al. 2014).

Pertinent to our investigation, there is a growing body of research that focuses on breast cancer treatment and social media and we refer readers to the excellent review by Zhang et al. (Zhang et al. 2016). We highlight that Marshall et al. (Marshall et al. 2016) illustrated breast cancer symptoms reported on MedHelp.org exhibit consistency with symptoms reported in the clinical setting. Attai et al. (Attai et al. 2015) demonstrated that breast cancer patients' have reductions in anxiety when attending patient-support groups via Twitter. Similarly, Portier et al. (Portier et al. 2013) found that breast cancer patients tend to report more positive emotions as they engage in online discussion.

Internet-based interventions have been applied to improve patients' adherence with mental health (Mohr et al. 2013) and antiretroviral medications (Horvath et al. 2013). However, these investigations are limited in that they have neglected how inferred personality traits influence adherence. While there have been studies focusing on the breastcancer.org forum (Zhang et al. 2016; Wang, Kraut, and Levine 2012; Jha and Elhadad 2010) that we use in this study, none investigated treatment adherence. Still, it should be recognized that Freedman et al. (Freedman et al. 2016) studied a large number of posts mentioning cancer treatments (including hormonal therapy) and identified treatment barriers that manifest from various aspects, including emotions, preferences and religious belief. Mao et al. (Mao et al. 2013) found that joint pain is the main reason patients stop taking aromatase inhibitors (AIs, a type of hormonal treatment) in online discussions of drug side effects and HTA discontinuation.

Our study is substantially different in that we we characterize HTA along three types of events: taking, interruption and completion. These are notable because taking events may provide insight into a patients' current state (i.e., when they are in the midst of treatment), and interruption and completion events allow for characterizing the difference between low and high adherence patients. This is also the first attempt to apply patient self-reported online information to predict their HTA status.

Data Preparation

Breastcancer.org is a non-profit organization that disseminates information about breast cancer to healthcare consumers. Additionally, it operates an online discussion board where breast cancer patients can seek, share, and respond to information about their experiences. The discussion board is organized into 80 forums, with more than 135,000 annotated topics. In this paper, we focus on the *Hormonal Therapy - Before, During and After*[1] forum. We collected all topics and posts within this forum published before June 22, 2016. In total, there are 9,996 patients who participated in 5,995 topics with more than 130,000 published posts.

Data Annotation

For the purposes of this study, we investigate discussions related to seven hormonal therapy drugs[2]: *Arimidex* (generic name: *anastrozole*), *Aromasin* (generic name: *exemestane*), *Femara* (generic name: *letrozole*), *Tamoxifen*, *Evista* (generic name: *raloxifene*), *Fareston* (generic name: *toremifene*) and *Faslodex* (generic name: *fulvestrant*). Since the same drug may be referred to in a variety of ways, we standardized the data by replacing the aliases of each medication (e.g., brand name) with their corresponding generic names. This study was deemed to be a non-human subjects investigation and granted exemption by the IRB.

There were 913,493 sentences voiced in the forum. We found 123,633 sentences (13.5%) contained at least one of the chemical names of interest. These sentences were communicated in 66,617 posts, published by 8,563 patients. We selected 1,000 sentences, at random, for annotation by human reviewers. The reviewers were asked to assign each sentence to one of seven options: 1) *Action: Taking medication*, 2) *Action: Stopped taking medication*, 3) *Action: Switched medications*, 4) *Plan: Take medication in future*, 5) *Plan: Do not take medication in future*, 6) *Plan: Not yet decided*, and 7) *None of the Above*. These options were based on our observation of how patients discuss treatments in this forum and guidance in a decision making codebook introduced by Beryl and colleagues (Beryl et al. 2017). For the purposes of our investigation (which focuses on two-class prediction), we labeled all of the first six options as *relevant* sentences and the final *None of the Above* option as *non-relevant* sentences.

We employed a majority rule annotation strategy with three reviewers who spent at least one month in this forum and were familiar with this topic. The first two reviewers annotated every sentence, while the third reviewer was employed to break ties. The primary two reviewers exhibited a *very good* agreement (Cohen's $\kappa = 0.82$) at relevant vs. non-relevant level; *good* agreement (Cohen's $\kappa = 0.72$) at the level of the seven options. After the third reviewer broke ties, we obtained 604 relevant sentences and 396 non-relevant sentences. The distribution of different options after annotation is shown in Table 1.

Adherence Event Extraction

To document adherence events with high precision, we adopted a hierarchical methodology similar to that invoked by others (Begum and Aygun 2014; Farid et al. 2014), which works as follows: First, we built an LR model to distinguish relevant from non-relevant sentences. Second, we applied a rule-based method to search relevant sentences for each adherence event. It should be noted that adherence events may not align with labeled actions.

Relevant Sentence Classification To distinguish between relevant and non-relevant sentences, we translated each sentence into a low-dimensional representation. This representation serves as the features for a LR model (as described below). We used the mean of the low-dimensional representation vectors of words, namely, word2vec (Mikolov and Dean 2013), in a sentence to represent the feature set for the classification model. We restricted our word2vec representation to words with a frequency of at least 5 instances in the hormonal therapy forum. We set the dimensionality of the word vectors to 100. We use the skip-gram model with negative sampling implemented in gensim (Řehůřek and Sojka 2010) to fit the word2vec model.

We used the LR model implemented in sklearn (Pedregosa et al. 2011) and applied a stratified shuffle/split

[1] https://community.breastcancer.org/forum/78

[2] http://www.breastcancer.org/treatment/hormonal/for_you

	Relevant						Non-relevant
Option	action:taking	action:stop	action:switch	plan:take	plan:not taking	plan:undecided	none-of-above
#Sent.	403	41	62	40	25	33	396

Table 1: The distribution of options in the 1000 labeled sentences (after the third annotator broke ties). The relevant versus non-relevant classes are approximately 3:2 in size.

method to create five cross-validation iterations. In each iteration, 80% of the instances were used to fit the LR model and the remaining 20% were used for testing purposes. All parameters of the LR model were set to their default values in the software package. The LR model achieved an AUC of 0.932 ± 0.010.

By adjusting the class weights, we tuned the LR model to achieve a precision of 0.882 ± 0.023 and recall of 0.882 ± 0.022. We then re-fit the model with all of the 1000 labeled sentences before applying it to extract the relevant sentences from the entire forum. Upon doing so, we obtained 80,510 relevant sentences that were distributed across 51,826 posts and authored by 8,023 patients.

Rule-based Event Extraction To extract additional sentences for each adherence event, we empirically created patterns that were based upon annotation experience. For example, when patients mentioned stopping a medication, the possible patterns could be 1) *Took me off*, 2) *Stop taking*, and 3) *Being off* a medication. Similarly, when patients mentioned that they were taking a treatment *vacation*[3], the possible patterns could be 1) *Vacation*, 2) *Holiday*, and 3) *Took a break* from a medication. When patients mentioned taking a medication, the possible patterns could be 1) *Started* and 2) *Been on* a medication. We refer the reader to Table 2 for additional examples of the patterns applied in our model.

	Pattern	κ.	Prec.
Completion	5 years, finished, ended, completed, done, ...	0.86	0.83
Interruption	back on, vacation, switch, took a break, took me off, gave up, stopped taking, ...	0.82	0.85
Taking	started, been on, stay on, ...	0.76	0.89

Table 2: A sample of the patterns applied for extracting adherence events. We account for variations in the spelling of a discovered word by applying word2vec (e.g., *yrs* for *years*, *vacations* and *vaca* for *vacation*).

To ensure high precision, we iteratively labeled events as follows: First, we extracted and labeled the completion events and removed these from further consideration. Second, from the remaining set, we extracted and labeled interruption events, which again were removed from further consideration. The remaining sentences were used to extract taking events. We followed the same process to extract patient groups with different adherence events. To assess the performance of this methodology, we directed two of the reviewers to assess 100 randomly selected sentences from each classified event category. The agreements, in terms of the Cohen's kappa, between these two reviewers and the precision for each type of events are summarized in Table 2. Finally, we obtained 1,172 posts published by 513 patients for completion events, 8,681 posts published by 2,525 patients for interruption events, and 15,116 posts published by 4,826 patients for taking events.

Emotion Analysis (R1)

To investigate if there exist significant differences in emotions between adherence event types when patients mentioned them, we randomly selected 500 sentences from each of the three adherence event categories. We chose sentences instead of entire posts because, in this forum, sentences are sufficiently verbose to convey information of interest (see examples below). By contrast, posts are too long to obtain precise emotion scores. These sentences were fed into the IBM Watson Tone Analyzer Service[4] to obtain emotion scores for each sentence, which together with IBM Watson Personality Insights service (see below) have been recently adopted for many emotion and personality related studies (Chirayil Subhash 2015; Mostafa et al. 2016; Thies et al. 2016).

The service returns scores with a range of 0 (the weakest) to 1 (the strongest) for five different emotion categories: *anger*, *disgust*, *fear*, *joy* and *sadness*. After obtaining emotion scores, we apply a one-way ANOVA test, with a significance level of 0.05, for each category. In this hypothesis test, the null hypothesis is that there is no significant difference in emotion when different adherence events are mentioned.

Figure 1 depicts barplots of the emotion scores for each adherence $\langle event\ type, emotion \rangle$ pair. Table 3 reports on the one-way ANOVA test results for each of the five tests. Each of the p-values are smaller than the predefined significance level of 0.05. This implies that there exists a significant difference between the emotions across the adherence event type.

From Figure 1, we found that patients tend to exhibit a relatively higher degree of anger when mentioning interruption events. This may be due to multiple reasons, such as frustration with the side effects of medications. A clear example of this phenomenon is in the following patient post:

[3]It should be noted that vacation events for certain medications were not captured by any label in the initial annotation task. However, upon re-examination, we determined that this group of sentences was not labeled as non-relevant. This is notable because it means that we can still extract such instances from the set of relevant sentences through a deterministic rule-based method.

[4]https://www.ibm.com/watson/developercloud/tone-analyzer.html

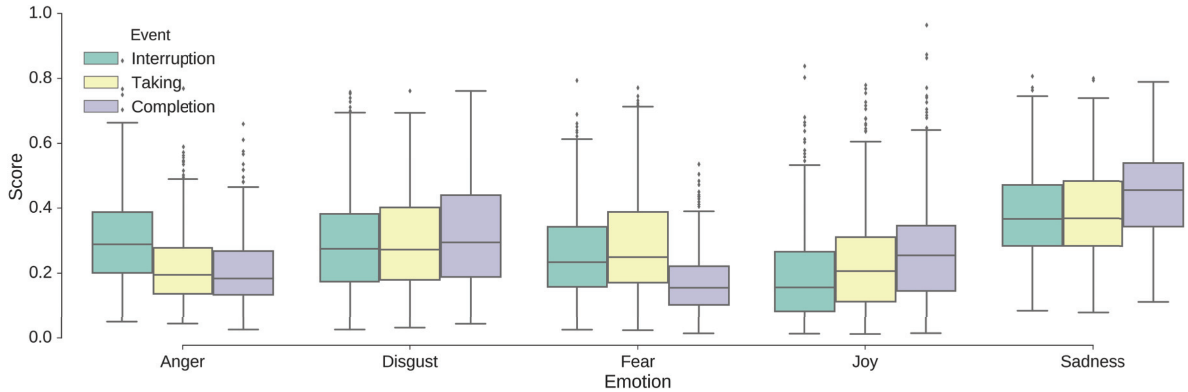

Figure 1: A boxplot of the emotion scores for adherence $\langle event\ type, emotion \rangle$ pairs. Mentions with interruption events tend to exhibit greater levels of anger. By contrast, mentions with completion events tend to exhibit greater levels of disgust, joy and sadness and lower levels of fear.

	Anger	**Disgust**	**Fear**	**Joy**	**Sadness**
F	100.449	6.866	107.977	25.327	40.592
p	< 0.001	0.001	< 0.001	< 0.001	< 0.001

Table 3: The results of the one-way ANOVA test on five emotions for three types of adherence events.

"*I hated the side effects and figured I'd die with or without the Letrozole so stopped after a couple months.*"

We also note that mentions with completion events tend to have a slightly higher level of disgust in comparison to the other two events. This may arise because, after five years of treatment, some patients may refuse to continue further treatment after re-balancing their quality of life and cancer recurrence. As one patient noted:

"*I finished 5 years of Tamoxifen and declined the Letrozole because my chance of recurrence was very very low and i wanted to feel more alive than the Tamoxifen allowed.*"

Yet it appears that completing a five-year treatment makes patients relatively less fearful and more joyful. This is not unexpected because, in spite of various side effects, approximately half of the women on hormonal therapy medications achieve this goal. For example:

"*I am happy to be done with the Anastrozole – but I am so glad I made the whole 5 years!*"

At the same time, completing a five-year treatment does not necessarily imply the end of hormonal therapy. Instead, it may just be the beginning of a second five-year treatment period. Moreover, the cancer may reoccur after the initial five year period. As one patient noted:

"*On a side note I was on Tamoxifen for five years and still got a recurrence so I'm not married to the idea of taking pills anyway.*"

Interruption and taking events did not exhibit a significant difference on disgust or sadness. However, there was a relatively higher joy score in taking event mentions, in comparison to interruption events. This is because patients who continue taking a medication may experience side effects that are quite different to the degree that patients who stop the medication do. As was voiced in one post:

"*I have been on Fulvestrant since January of 2014, very little side effects.*"

Still, not everyone voices a lower degree side effects when taking hormonal therapy medications. It should be noted that some patients who start taking medication often fear the side effects. As one patient noted:

"*I just started tamoxifen 3 days ago and i am sitting here in fear of getting fat ...*"

Association Between Personalities and Adherence (R2)

Next, we investigate if there exists an association between specific personality traits and HTA. Specifically, we focus on which personality traits are associated with the patient group with interruption events and the patient group with completion events. We apply a classical LR analysis to study this problem. To obtain personality scores, we leverage the IBM Watson Personality Insights service[5].

This service inspects documents (e.g., emails, tweets or posts) and returns personality characteristics along three dimensions: the "Big Five" traits (John, Naumann, and Soto 2008), values, and needs. In this paper, we only apply the "Big Five" traits, the facets of which are shown in Figure 2. Note that the scores for categories are reported as percentiles instead of absolute measures. For instance, a 90% on *Extraversion* suggests that the writer is more extroverted than 90% of the people in the population.

[5]https://www.ibm.com/watson/developercloud/personality-insights.html

After applying a threshold of 3,000 published words or greater (reaching the service's maximum precision), there were 1,402 patients who mentioned interruption events and 348 patients who mentioned completion events. We conduct a LR analysis using the 35 personality trait scores for the 1,750 patients.

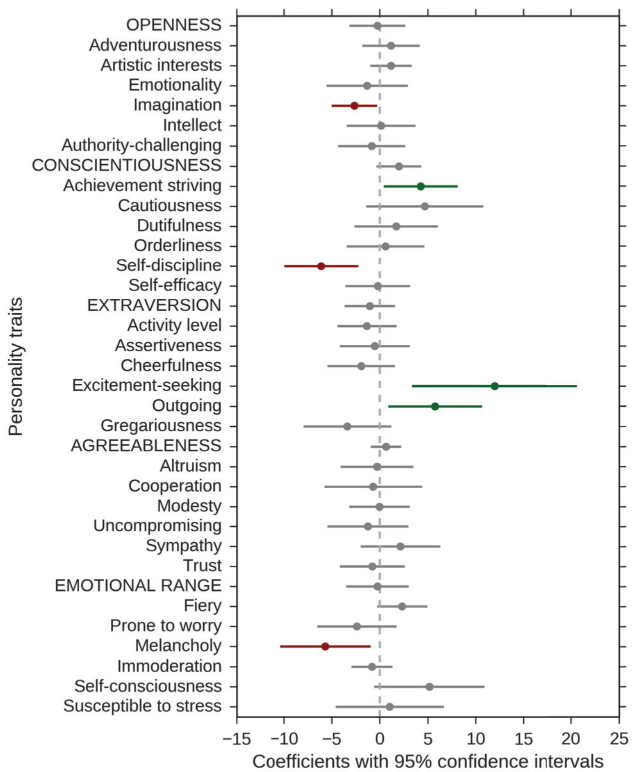

Figure 2: The coefficients and their 95% confidence intervals for the 35 personality traits. The coefficients are grouped by their categories: the labels in uppercase are the Big Five and the lowercase are their facets.

Personality	Coef	Std Err	Z	$P > \lvert z \rvert$
Excitement seeking	11.973	4.402	2.720	0.007
Self-discipline	-6.105	1.967	-2.104	0.002
Outgoing	5.767	2.495	2.312	0.021
Melancholy	-5.680	2.405	-2.361	0.018
Achievement striving	4.268	1.963	2.174	0.030
Imagination	-2.657	1.209	-2.198	0.028
Log-Likelihood				-377.72
LL-Null				-422.83
LLR p-value				0.0006

Table 4: The significant predictors in the logistic regression (LR) model, ranked by their absolute coefficients.

Figure 2 shows the coefficients and their 95% confidence intervals (sans intercept). Note that the coefficients are basically indicative of the log-odds of the probability that a user is in the patient group with completion events. The coefficients with intervals not crossing the $x = 0$ vertical line are the most notable. The positive significant coefficients (shown to the right in a dark green color) suggest the personality traits are more related with the patients with completion events, while the negative significant coefficients (shown to the left in a dark red color) suggest the personality traits are more related with the patients with interruption events. A higher absolute coefficient value indicates a stronger association. Table 4 shows the statistics for six personality traits that are associated with HTA in a statistically significant manner. The model is significant in comparison against a baseline null model according to a likelihood ratio test (p = 0.0006).

Definitions of the personality traits presented in Table 4 are drawn from the service and listed below:

- **Excitement seeking:** *A need for environmental stimulation.*
- **Self-discipline:** *The capacity to begin tasks and follow through to completion in spite of boredom.*
- **Outgoing:** *Interest in and friendliness towards others; socially confident.*
- **Melancholy:** *Normal tendency to experience feelings of guilt, sadness, hopelessness, or loneliness.*
- **Achievement striving**: *The need for personal achievement and sense of direction.*
- **Imagination:** *Openness to creating an inner world of fantasy.*

Among the Big Five, Agreeableness is the only personality that does not have significant facets. The facets of *excitement seeking* (Extroversion), *outgoing* (Extroversion) and *achievement striving* (Conscientiousness) have significant positive association with patients with completion events. In contrast, the facets of *self-discipline* (Conscientiousness), *melancholy* (Emotional range), and *imagination* (openness) have significant positive association with patients with interruption events. Note that Conscientiousness has two facets with effects in opposite directions. We discuss our findings further in the Discussion section.

Interruption Events Prediction (R3)

In this section, we investigate the extent to which the existence of interruption events in the future can be predicted by earlier published posts. To do so, we focused on two classes of forum patients. The first corresponds to patients who mentioned interruption events, but never mentioned completion events. The second corresponds to patients who mentioned completion events. For each user in these classes, we extracted all posts (in the hormonal therapy forum) that were published before their first mention of an interruption or completion event. We sampled from the two patient groups to study an equal number of individuals in each class, as per (De Choudhury et al. 2016).

To perform binary classification, we selected the 2000 unigrams and bigrams of *stemmed* words with the highest term frequency - inverse document frequency (TF-IDF) values as features. Due to the sparsity of the feature space, we apply

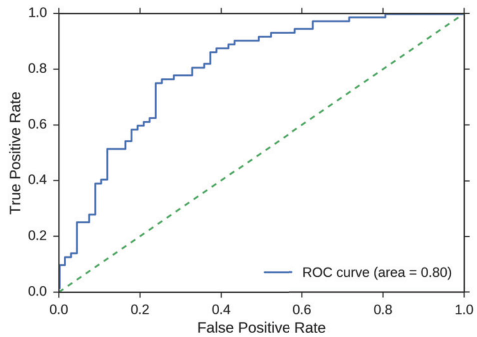

Figure 3: The ROC curve of the LR model for predicting Interruption events, with unigrams and bigrams of stemmed words as features.

LR with ridge regularization. We set all of the parameters of the model as default. To evaluate the performance of the model, we apply a stratified shuffe/split strategy to perform five-fold cross-validation. We measure performance using accuracy, precision, recall, F-score, and AUC.

Finally, there were 1,347 patients who mentioned interruption events and 347 patients who mentioned completion events. To balance the classes, we randomly sampled 347 patients from patients with interruption events (for a total of 694). Table 5 shows the performance of the model. The AUC of the model evaluated with five-fold stratified cross-validation is 0.801 ± 0.020. To illustrate the ROC curve, we report the AUC (with mean value) in Figure 3.

Precision	0.709 ± 0.018	F1	0.723 ± 0.024
Recall	0.739 ± 0.046	Accuracy	0.717 ± 0.018

Table 5: Performance of the LR model for predicting Interruption events.

To obtain insight into the association between features and classification, we report the 20 most informative features for each class in Figure 4. These features are selected based on the rank of their mean coefficients in the classifiers that are obtained through the five-fold cross-validation. Features with a positive and negative weight correspond to the patient groups communicating interruption and not communicating interruption events, respectively. The features show that patients beginning a medication appear to be more likely to experience an interruption event in comparison to patients who have taken it for many years. Mentions about side effects, such as depression, are also strong signs that an interruption event will be realized in the future.

Discussion

Insights on Factors Related to HTA

Our research is based on self-reported patient information in an online health forum. Self-reported information has the potential to provide a candid view of patients' daily experiences, thus allowing for more non-clinical insights into the understanding HTA. For instance, our emotion analysis shows that patients who mentioned interruption events often exhibit a strong emotion of anger. If care providers could continuously monitor patients' posts (or be provided with interpretation services in the event patients do not wish doctors to listen in on everything they have to say), they may be provided with signs of potential interruption events before they occur (e.g., through rising rates of an anger emotion).

Our interruption event prediction model also suggests that interruption events are more likely to transpire for patients who are at the beginning of a hormonal therapy drug regimen and/or manifest sides effect (e.g., depression). Care providers may consider paying special attention to this type of patient. However, even for those patients who have completed a five-year protocol, they may have strong sadness when mentioning completion events. Cancer survivorship is complex and it has been shown that completion of a treatment course can be accompanied by symptoms similar to post-traumatic stress disorder (PTSD) (Amir and Ramati 2002; Kornblith et al. 2003). It is quite possible that the transition from the known setting of adjuvant treatment to the "unknown" setting of routine surveillance could trigger sadness, which is manifest in the forum writings.

Our findings indicate that long-term consistent support may be needed to correct patients perspectives and improve their overall treatment experience. Given that the common practice in breast oncology clinics is to see patients twice per year while they are receiving long-term hormonal therapy, ancillary triggers for impending HTA problems, such as prompting patients for reflective comments through consumer health informatics interfaces, should be pursued.

Personality Traits and HTA

Our findings in personality analysis show that patients who completed treatment successfully are significantly more likely to display the traits of Extraversion (*excitement seeking* and *outgoing*) compared to patients who started but did not complete treatment. This is aligned with traditional offline adherence studies where Extraversion has been found to be positively associated with adherence to treatment with antidepressants (Cohen et al. 2004). Courneya et al. (Courneya et al. 2002) showed association between Extraversion and exercise adherence. Interestingly, our interruption event prediction model also shows that *exercise* is one of top informative predictors for completion events prediction (see Figure 4).

Facets of Openness to Experience (*Imagination*) and Neuroticism (*Melancholy*) are found to be negatively associated with patients with completion events in our model. This is also aligned with related literature in which both of them were found to be associated with low adherence (Axelsson et al. 2011; Bruce et al. 2010; Axelsson et al. 2013; Alexopoulos et al. 2016). While Conscientiousness has been found to be positively correlated with medication adherence in patients with chronic disease (Axelsson et al. 2011), we found two of its facets (*achievement striving*, *self-discipline*) have opposite effects on HTA. The finding of a negative effect of self-discipline on HTA is contrary to studies on adherence to diet and exercise (Ganiyu et al. 2013). We do not

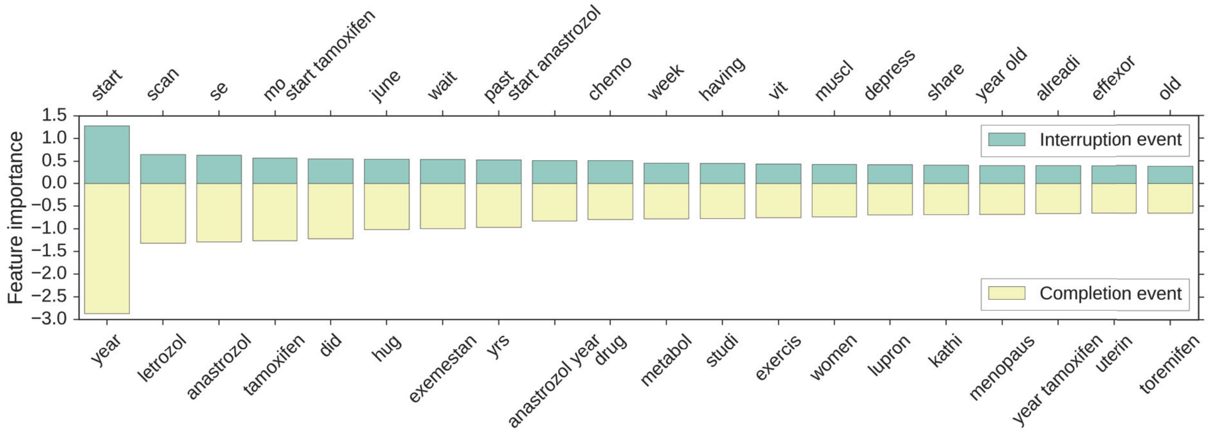

Figure 4: The 20 most informative features for each class. Features with positive weights correspond to the patient group with Interruption events, while features with negative weights correspond to the patient group with Completion events. The larger the absolute score for a feature, the greater its importance in the model.

know the reason beyond this discovery at this time, but believe it provides an opportunity for future investigation.

Impact on Social Health Studies

There are three main messages from our investigation. First, we demonstrate that it is feasible to study the adherence behavior of breast cancer patients undergoing hormonal therapy by analyzing their posts in an online community. Second, we show that emotions and personalities, which are scarce in traditional medical resources, but can be automatically extracted from self-reported information, may provide further insights into the nature of HTA. Finally, our interruption event predicting model built upon patients' history posts suggests the possibility for proactive interventions to improve overall adherence.

Limitation and Future Work

There are several limitations in our work that we wish to highlight. Although breastcancer.org is large, it may not contain a representative samples from the full spectrum of breast cancer patients. Methodologically, we rely upon a rule-based approach to obtain sentences related to different adherence events. While this method promises a high precision, it neglects related sentences that do not quite follow the predefined rules. As such, there are clearly opportunities for enhancing the recall of this model. Another limitation of this work is that we only examine how word (in the form of unigrams and bigrams) features can be leveraged to predict interruption events. More semantically-meaningful features could be potentially applied to improve the model. For instances, such features could be derived from a patient's posting statistics, self-reported diagnosis and treatment history, and language categories. In this investigation we only considered emotions when patients mention different adherence events. This leads to an incomplete picture of the population and it is necessary to investigate how emotion changes before interruption events actually occur. Similarly, the extent to which the previous posts are predictive to interruption events is also deserving of further study. It will be interesting to investigate why self-discipline is negatively associated with HTA.

Conclusion

In this paper, we investigated hormone therapy adherence (HTA) based on patient self-reported information in a large, longitudinal online breast cancer forum. We focused on a dataset collected from breastcancer.org and characterized adherence behavior with three types of events: taking (medication), interruption (of the treatment regimen) and completion (of five-years of treatment). From an emotional perspective, we found that when patients mention taking (medication) events, they have a relatively higher rate of fear (for potential side effects); when patients mention interruption events, they have a relatively higher rate of anger; and when patients mention completion events, they exude more joy and less fear, but also experience relatively higher sadness. Most of our personality analysis confirmed results from treatment adherence studies based on data collected from offline settings (e.g., surveys), but we also found self-discipline is negatively associated with completion events, which should be interesting to be investigated in future. Our interruption event prediction model suggested that patients at the beginning of their treatments are more likely to realize interruption events in the future than patients who successfully make it through several years of treatment. We have demonstrated that patient-provided information in an online breast cancer community can be potentially applied to study HTA. We believe our methodology can be adopted to study adherence to treatment on other health issues through patient self-reported online information.

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