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Beyond an OSN Post: Looking at Emotional Valence and Request of Support/Information

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Abstract

Rheumatoid arthritis is a chronic autoimmune disease that does not have a cure. Therefore, it is important for patients to receive support, which would allow them to ask questions and express their feelings. This study examined online social networks for patients with rheumatoid arthritis to better understand the emotional valence of their initial posts and whether there was an association between posts with negative emotional valence and requesting support/information. We hypothesized that the majority (more than 50%) of the emotional valence of initial posts would be negative, and that there would be an association between negative emotional valence and support/information. Nine hundred eighty-six initial posts from a rheumatoid arthritis online social network via Reddit were coded as either positive, negative, neutral, or mixed. In addition, the initial posts were coded as either requesting support/information, offering support/information, neither requesting nor offering support/information, or both requesting and offering support/information. Negative was the most common emotional valence in the initial posts followed by mixed, neutral, and positive. There was also an association between initial posts that had a negative emotional valence and requested support/information, and initial posts that had a negative emotional valence but did not request support/information. As a result, the implications of this study indicate the need for additional information and support to be provided to patients with rheumatoid arthritis, so they can have a better experience and an easier way to cope with their illness.

Introduction

Chronic pain affects a variety of aspects of life including relationships, work, and leisure (Kristiansen et al., 2012). In order to learn more about how individuals with rheumatoid arthritis receive support, we examined the emotional valence of initial posts on an online social network for patients with rheumatoid arthritis. This information will provide an understanding of the experiences rheumatoid arthritis patients are having, how they are coping with their illness, and will indicate whether additional information or support from healthcare professionals is needed.

Rheumatoid Arthritis

Rheumatoid arthritis (RA) is defined as, "a chronic progressive autoimmune disease characterized by inflammation of synovial joints, causing immense pain and joint stiffness" (Barker & Puckett, 2010, as cited in Poh et al., 2017, p. 374). Throughout the duration of their illness, patients may experience a decline in physical functioning, psychological challenges, and emotional challenges (Kristiansen et al., 2012; Iaquinta & Larrabee, 2004). Activities that patients may have previously enjoyed may be affected by the physical pain they endure daily (Krol et al., 1993). Additionally, negative feelings such as anger, frustration, depression, and fear all play a part in how patients view their illness and how they cope with it (Iaquinta & Larrabee, 2004). These different challenges affect the overall quality of life of RA patients.

Types of Support

In order to discuss aspects of their illness and receive support, many patients use different resources including physicians, family, and online social networks (Mehta & Atreja, 2015; Poh et al., 2017). Support from a doctor is necessary in order to gain trust and learn how to cope with a new diagnosis. Physicians are able to provide choices, listen to patients, and encourage patients to ask questions (Gensichen et al., 2009). In addition to a strong doctor-patient relationship,

family support for patients with an illness is also extremely important because they are able to provide the support that is necessary for patients to have a better experience and health outcome (Cooper & Gilbert, 2017; Poh et al., 2017). They may also be able to help manage the condition by ensuring access to treatment and easing any obligations (Cooper & Gilbert, 2017).

Finally, online social networks (OSNs) are a relatively accessible and easy way for patients to connect with other people (Mehta & Atreja, 2015). OSNs and online support groups are online communities where participants help and support each other and discuss their lives with their diagnosis (Mehta & Atreja, 2015; Wright et al., 2020). According to Mehta and Atreja (2015), OSNs serve two purposes: emotional support and information-seeking. By seeking out information anonymously, patients are asking questions about the illness and are learning about different ways to identify or live with the illness.

Online Social Networks for Chronic Pain

Researchers have examined how patients with chronic pain such as endometriosis and fibromyalgia use OSNs like Instagram to inform and give visual representations of their illness, but research examining OSNs and RA is relatively rare (Sendra & Farré, 2020). Wright and colleagues (2020) examined pain disclosure in OSNs for patients with rheumatoid arthritis and fibromyalgia. They found that initial posts with pain disclosure had more engagement from OSN users and more replies than initial posts without discussion of pain disclosure. Given that OSNs have been effective for patients with endometriosis and fibromyalgia, it would be beneficial to learn more about patients with RA and their viewpoint of their illness.

Current Study

Based on the use of OSNs for other chronic conditions and research about RA, this study examined OSNs for patients with RA to better understand the emotional valence of their initial

posts, and any association between posts with negative emotional valence and requesting support/information. In doing so, two questions arose: the first question focused on the emotional valence of initial posts, and the second question focused on whether there was an association between emotional valence and requesting support/information. Due to the decline in physical functioning, psychological challenges, and emotional challenges that patients with RA often face, it seems more likely that RA patients would discuss more negative experiences than positive experiences on an OSN (Kristiansen et al., 2012; Iaquinta & Larrabee, 2004).

Therefore, we hypothesized that the majority (greater than 50%) of the emotional valence of initial posts on this online social network would be negative (*Hypothesis 1*). Additionally, posts may be more negative because patients may want to supplement information from their healthcare professionals to gain more information, reassurance, and additional support (Poh et al., 2017). Thus, if the majority of the posts are negative, patients may be in need of help or additional support and/or information. Consequently, an exploratory hypothesis was developed: There will be an association between posts with a negative emotional valence and requesting support/information (*Hypothesis 2*).

Method

Procedure

Public data was acquired from the Reddit RA OSN (http://www.reddit.com/r/rheumatoid) using jsoup, a Java-based code library for HTML parsing (Hedley, 2017). The IRB of the University of California, Riverside allowed an exception from review due to the public availability of the data from the RA OSN. This data was also used in a previous study that found evidence of how pain disclosure unfolds in everyday naturally-occurring social contexts (Wright et al., 2020). The data retrieved included the individual posts with the username, post time, and

position in the thread. A total of 1,122 posts were retrieved over a period of four years, but 136 posts were excluded from analyses due to broken links, links without any text from the original user, and titles without an initial post. There is no demographic data from the participants because contact was not made with any of the users from the OSN.

Measures

Emotional Valence

The four coding categories for emotional valence were positive, negative, neutral, and mixed. Each coding category was mutually exclusive, which means only one of the four coding categories was coded for each initial post. See Table 1a for coding definitions and examples.

Four research assistants coded coding categories as either present (1) or absent (0). The coding team reviewed the definitions of the four coding categories and looked at different examples for each. The coding team then coded a sample subset of 200 posts and kappa was calculated to make sure agreement was acceptable. Any discrepancies between the coding team were discussed and reviewed. The coding team then coded the rest of the posts, and kappa (a measure of inter-rater reliability for categorical data) was calculated again for the full data set. When one coder was removed from analyses due to low agreement with the other three coders, kappa was 0.68, an increase from 0.59 with all coders. A total of four posts for emotional valence had no majority rule because each coder coded a different mutually exclusive coding category. In those four cases, the second author served as a tie breaker.

Support/Information

The four coding categories for support/information were requests support or information, offers support or information, neither requests nor offers support or information, and both requests and offers support or information. See Table 1b for coding definitions and examples.

The coding procedure was identical to that of emotional valence. Overall agreement for support/information for all coders yielded a kappa of 0.82 and increased to 0.86 upon removal of one coder due to low agreement. Again, one post for support/information had no majority rule, so the second author served as a tie breaker. Note that the coding procedure for support/information requests was distinct from the coding procedure for emotional valence. That is, the negativity of posts was not considered in coding for support/information requests, only whether the user explicitly made a relevant request.

Analytic Plan

Descriptive statistics assessed the frequency and percentage of initial posts that were negative in comparison to positive, neutral, and mixed (testing *Hypothesis 1*). Because the data are categorical, a chi-square test of independence was used to examine the association between initial posts that had a negative emotional valence and requested support or information (testing *Hypothesis 2*).

Results

Emotional Valence

In descending order, the frequency of emotional valence coding categories is negative (n = 448, 45.44%), mixed (n = 313, 31.74%), neutral (n = 162, 16.43%), and positive (n = 63, 6.39%). Thus, *Hypothesis 1* is not strongly supported. Instead, the data shows that just under half (45.44%) of the initial posts are negative. However, in combination with the mixed category, there are a total of 77.18% (n = 761) of initial posts with some indication of negative emotional valence, providing some support for *Hypothesis 1*.

Support/Information

A chi-square test of independence reveals that the pattern of support/information requests

differ significantly between negative and non-negative posts, $\chi^2(1, N = 986) = 22.064$, $p < .001$, $\varphi = 0.17$ (Table 2 and Figure 1). Within negative posts, 89% of posts requested support or information, whereas only 78% of non-negative posts included a support or information request. Put another way, 49% of posts that requested support or information were negative, whereas only 29% of posts that did not request support or information were negative. These results support the exploratory hypothesis of an association between initial posts with a negative emotional valence and requesting support/information, such that requests for support/information tend to co-occur with negativity in posts.

Discussion

It is especially important for patients with rheumatoid arthritis to receive support, ask questions, and express their feelings, because rheumatoid arthritis is a chronic autoimmune disease without a cure. We examined emotional valence and support/information requests on an OSN to understand naturally occurring conversations about RA. The results showed that a plurality of posts were negative, with the least common type of post being positive, and that there was a small but significant association between posts with negative emotional valence and requests for support/information.

The initial posts from the RA OSN included more negative posts than any other category. In combination with the mixed category, there was a much higher percentage of some amount of negativity than purely neutral or positive posts. This may be because patients with RA have psychological and emotional challenges, which include feelings of anger, frustration, sadness, despair, and helplessness (Poh et al., 2016). These feelings often arise when others in their lives are unable to empathize with their situation, or when they feel as if they have lost independence due to RA (Poh et al., 2016). These reasons are an indication as to why patients may go on an

OSN and discuss these negative feelings with others.

According to Cho (2017), negative emotional disclosure is a sign of others seeking help due to stress from a negative event. By going on an OSN and writing a negatively-valanced post, patients may be indicating that there is something wrong with the treatment they are receiving, that they are not coping well with their illness, or that they may be having a bad day. Additionally, some information patients seek include questions about their course of treatment, unanswered questions after visiting their health care provider, or information about a change in diet or exercise habits (Huh et al., 2013). Assessing the information that users request on an OSN provides a better understanding as to why posts with a negative valence were more common in posts that requested support/information.

In rare instances, we identified posts with a positive valence. Even in combination with mixed posts, which include positivity and negativity, there was still a low number of posts that were considered positive. In a study conducted by Ostuland and colleagues (2014), when asked to describe their everyday life, RA patients did not mention anything positive but instead talked about times of fear, embarrassment, and grief. Our findings may be an indication that there are more negative experiences than positive experiences throughout the day for individuals with RA.

Strengths, Limitations, and Future Directions

As a result of each post being written with a non-identifiable username, it would have been difficult to contact the patients and ask them additional questions. Due to this limitation, we were not able to learn more information about the OSN users. Additional information may have provided a deeper insight of overall demographics of who is using the OSN. Despite this limitation, the anonymity of an OSN allows patients to comfortably ask questions and describe

certain aspects of their illness. This naturalistic environment allows us to see what the patients truly want to discuss, instead of it being filtered to what researchers might want to hear.

Future research can gather demographic data to better understand the generalizability of our findings. Gathering information from OSN users such as age, socioeconomic status, and how long they have been diagnosed with RA would give a better understanding of the users of the OSN. Gathering information about emotional experiences would also be beneficial to determine whether individuals tend to be more positive or negative in their daily lives. For example, users of an OSN could provide multiple daily reports of their general emotions throughout the day for one week. This would allow us to determine whether the users of an OSN tend to be mostly negative or positive throughout the day, how they feel after posting on an OSN, and how they are coping throughout the day, instead of assuming this information from an OSN post.

Conclusion

In conclusion, this study found that most initial posts on this RA OSN had a negative emotional valence. Additionally, patients were more likely to ask for support or information in negatively-valanced posts. Results from this study provide insight for healthcare professionals regarding the importance of making sure patients are given information in a way they can understand, answering all questions from patients, recognizing what knowledge patients need to cope more effectively, and providing credible resources for them to turn to if necessary.

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Table 1a

Emotional Valence Definitions and Examples

Coding Category	Definition	Example
Positive	Any indication of positivity including positive topics, positive reframing of situations, or any indication of happiness, hopefulness, etc.	"You're all so wonderful and supportive!! I hope you all find remission and stay there :) and realistically, may the flares be mild and the meds effective!!"
Negative	Any indication of negativity including negative topics, or any indication that the user was sad, angry, worried, etc.	"Curling my fingers around the steering wheel aches. Gripping the steering wheel aches. Taking a shower aches. But driving. Oh my god. Sorry. I'm in flare up mode and just needed to whine. :(thanks for listening."
Neutral	No indication of being positive or negative and it is written in a matter-of-fact way.	"Has anyone else made the shift from Enbrel to Humira and been successful? Has anyone ever been able to go back to Enbrel after taking a "break" with a different med?"
Mixed	A combination of both positive and negative tones.	"I'm scared, excited and sore (medrol injection started wearing off 2 days ago) and finding concentrating on work to be impossible today"

Note: The sample posts were copied verbatim from the OSN.

Table 1b

Support/Information Definitions and Examples

Coding Category	Definition	Example
Requests Support or Information	Any explicit or implicit request of support, information, comfort, validation, advice, suggestions, etc.	"If you've got a cold or the flu do you take your weekly dose? I'm set to take mine today and have come down with a nasty flu."
Offers Support or Information	Offering support, information, advice, or suggestions. Does not include any background information provided when requesting support or information.	"If there are any young people out there who are fearing the worst or any older people! Ask me your questions! I've been on all the common NSAIDs and I'm on my 3rd biologic. GO!"
Neither Requests nor Offers Support or Information	Does not request or offer support or information.	"My boyfriend has been giving me my injections because I couldn't bring myself to do it. Tonight he fell asleep on the couch and I didn't have the heart to wake him. So, I just grabbed my shot, took a deep breath, and DID IT!"
Both Requests and Offers Support or Information	Any indication of asking a specific question or for support or advice, and providing support or information that may help someone else.	"So, when I am feeling sore and stiff I try to stretch it out as much as possible. One thing that really helps me is hanging upside down off of the couch. Sometimes I even try to do a hand stand against the wall. Am I strange? What sort of stretches do you do?"

Note: The sample posts were copied verbatim from the OSN.

Table 2

Association between Negative Emotional Valence and Requesting Support/Information

	Requests Support/Information	Does Not Request Support/Information
Negative emotional valence	399	49
Other emotional valence	417	121

Note: The numbers indicate the frequency of posts.

Figure 1

Association between Negative Emotional Valence and Requesting Support/Information