The Effect of Information Exchange Activities on Literacy in Online Health Community: The Evidence from PatientsLikeMe

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Abstract: Online health communities (OHC) consist of individuals with shared health-related interests who exchange health-related information among themselves and for the benefit of others. Unfortunately, a notable issue within these communities is the dissemination of a substantial volume of inaccurate health information by various online health groups. Nevertheless, a dearth of research examining the impact of information-seeking activities within OHCs exists. This study aimed to examine the influence of direct and indirect health information-seeking behaviors, specifically among users diagnosed with Type 2 diabetes who have reported complications in OHC, also called claims. Employing association rule mining (ARM) techniques, user data from PatientsLikeMe were extracted to capture information on users’ reported complications subsequent to being diagnosed with Type 2 diabetes (N = 6371). Subsequently, we utilized zero-inflated negative binomial regression (ZINB) to evaluate the effect of direct and indirect information search activities on false notes, including their interaction of them. The outcomes of this investigation have the potential to offer patients valuable insights regarding the reliability and trustworthiness of information derived from OHCs.

Keywords: online health community; online health information; online health literacy; false note; information exchange

1. Introduction

The emergence of information and communication technology has resulted in a paradigm shift in the realm of consumer information dissemination, transitioning from offline channels to online platforms. This transformation has resulted in online health communities (OHCs), representing a novel and consumer-centric agora for sharing valuable information [1]. OHC functions as a virtual environment where consumers share ongoing and spontaneous information, facilitating the acquisition of decision-making insights aligned with their individual goals. This phenomenon has ushered in a paradigmatic shift in the exchange of information between consumers themselves, as well as between consumers and healthcare providers, surpassing the traditional framework of information exchange predominantly initiated by providers and received by consumers [1,2]. OHCs, serving as platforms for information exchange, foster relationship-building among members through a shared medium, enabling users to achieve desired benefits aligned with their respective goals (e.g., geographic, temporal, and privacy-related non-constraints). They are particularly prominent in the healthcare market, which is characterized by heightened information search needs, uncertainty, and decision-making risks [3].

Leveraging the capabilities of the internet, OHCs facilitate interactions among members with shared health-related concerns, thereby augmenting the effectiveness and efficiency in addressing their individual needs, in contrast to traditional health-related websites...
that solely offer information retrieval functionalities to members [4]. Nonetheless, OHCs possess a distinct characteristic in that healthcare information, unlike information about everyday consumer goods, entails a relatively elevated level of complexity and expertise, rendering consumer decision-making processes rife with uncertainty and inherent risk [5]. Healthcare consumers’ decisions carry profound consequences, often involving life and death. Accordingly, the imperative to seek information for decision-making is notably elevated, necessitating a heightened requirement for accuracy in the information obtained. Furthermore, healthcare-related information is comparatively complicated, demanding a certain level of expertise to comprehend effectively [6]. Historically, healthcare decision-making primarily revolved around the provider. However, patient empowerment and patient engagement via OHC have highlighted the participant role’s growing significance. Consequently, the consumer has evolved from being the object of healthcare decision-making to being recognized as a subject of decision-making alongside the provider [7,8]. Healthcare consumers, assuming an active role as decision-makers, generate personalized information to address their specific circumstances and employ internet-based information search behaviors to alleviate uncertainty [9]. Within the internet community (i.e., OHC), which has emerged as a prevalent source of health information, a significant number of consumers routinely seek such information online [10,11].

Online health information (OHI) distinguishes itself from traditional media by its virtual existence within the internet, enabling participants (i.e., users) to transcend economic and geographical constraints, thus leading to minimal access barriers. Moreover, the interactive nature of the internet renders it an ideal platform for disseminating information, facilitating consumers’ extensive search for health-related information due to its continuous and organic structure. Traditionally, consumers’ health information search behavior revolved around local professionals and mass media, with consumers who had prior healthcare purchasing experiences communicating their perceived experiences to other consumers before making their own purchase decisions [12]. Nevertheless, as the internet has advanced and the proliferation of OHI websites has become prevalent, healthcare consumers can now leverage the extensive array of OHI options. Furthermore, this approach fosters the development of social and personal health comprehension, thereby reducing uncertainties surrounding the consumer’s health status [12,13].

Although numerous investigations have raised concerns regarding the uncertainty associated with OHI within OHCs, a limited number of studies have examined the relationship between users’ direct and indirect OHI behavior in OHCs, as well as their interaction effect on the exchange of misinformation [14]. This study investigates the exchange and search activities of users self-identifying as having Type 2 diabetes within an OHC to explore the presence of consumer information search behaviors about OHI within the OHC. In pursuit of this objective, the present study employed association rule-mining (ARM) techniques to uncover instances of inaccurate health literacy about complications reported by patients with the same disease within OHCs [15]. Consequently, an association system was established to capture the occurrence of inaccurate health literacy (i.e., false notes) generated within OHCs. Furthermore, following Wilson [16]’s information behavior model, this study aims to investigate the disparity in the quality of information for decision-making, focusing on health literacy, as well as users’ search behaviors with high and low involvement within OHCs (i.e., direct and indirect OHI search behavior in this study). Specifically, by investigating the dynamics of social activities and their influence on health misinformation, this study aims to contribute valuable insights that can be utilized to improve social activities related to OHI dissemination. Ultimately, the findings from this study have the potential to inform strategies and interventions that promote accurate health information sharing, empower individuals to make informed decisions, and enhance public health outcomes for individuals with Type 2 diabetes. Furthermore, this study aims to ascertain whether active participation and engagement in consumer information search activities within OHCs contribute to improving health literacy, thus aligning with the quality of user information utilized to mitigate the spread of misinformation.
2. Literature Review and Hypothesis Development

2.1. Healthcare Decision-Making

Healthcare decision-making encompasses inherent uncertainties and trade-offs distinct from decision-making in other industries. These uncertainties arise from the complexities associated with diagnostic procedures, the availability of treatment options, varying patient preferences and values, and cost considerations [17]. Uncertainty in healthcare decision-making arises from multiple factors, including diagnostic accuracy, disease progression, and treatment effectiveness. Incorrect patient observations, inaccurate medical diagnoses, and differences in data interpretation can influence this uncertainty. Although it cannot be eliminated, healthcare providers utilize various systems and devices to regulate and control uncertainty to enhance decision-making processes [17,18]. Mishel et al. [19] analyzed the sources of uncertainty in health care decision-making by categorizing patients’ experiences of disease-related uncertainty as ambiguity, complexity, insufficient information, and unpredictability. Babrow et al. [20], in an expanded model, categorized the forms and factors of uncertainty in health care. Lipshitz and Strauss [21] proposed a two-dimensional classification of uncertainty in health care decision-making. To reduce uncertainty in healthcare decision-making, Han, Klein, and Arora [18] emphasized the importance of information exchange between providers and consumers, along with their respective roles in the decision-making process.

2.2. Online Healthcare Information Search

Online health information (OHI) has unique features, such as anonymity, accessibility, and interactivity. Unlike traditional health information, OHI can be created by anyone, which introduces the possibility of reliability and accuracy issues. While the adverse effects of non-expert groups producing OHI exist, the potential benefits of OHI outweigh these concerns. However, it is important to recognize that incomplete or inaccurate OHI may confuse consumers and producers, potentially diminishing the positive impact of information searches on reducing uncertainty [22]. The limited reliability and prevalence of inaccuracies in OHI stem from its inherent characteristics, where factors such as peer review, regulations, and laws are often lacking or insufficiently established. Consequently, consumers risk encountering inaccurate information when utilizing web pages that lack proper peer-review mechanisms [10,22]. Metzger [23] argued that information filters and moderation mechanisms that have been applied to validate and support relatively limited amounts of information may not be effective in this new environment, and that in the absence of such controls, information evaluation and validation, which is directly related to the reliability of information, must be conducted by the consumers themselves, who are the main actors in online health navigation.

2.3. Online Healthcare Community

Patients are important sources of information, actively participating in OHC through diagnostic tests, treatments, and communication. However, inaccuracies or deficiencies in patient-generated information can negatively impact the healthcare process, potentially leading to inaccurate decision-making. Therefore, improving patient knowledge and information searches is crucial for enhancing the accuracy and effectiveness of healthcare decisions [1]. With the rise of patient empowerment and patient engagement, users’ active engagement in OHI search activities within OHCs has increased significantly. Many consumers utilize diverse OHCs as platforms for health information searches and exchange activities [10]. Cotten and Gupta [24] analyzed the reasons behind consumers searching for online health information (OHI) and the characteristics of consumer groups who conduct such searches. Bundorf, et al. [25] suggested that individuals’ desire for OHI is affected by their traits and need to obtain health-related knowledge from multiple sources. Escoffery et al. [26] conducted a survey of college students at two university institutions to analyze the extent to which younger consumers are active in online health information search and their online health information search practices. The study found that 72.9% of the
respondents had used the Internet to search for health information, and 94.3% of the respondents used the accuracy of information on OHI sites as a very important criterion in choosing an online health information search medium. In addition, 78.5% said that the credibility of the author of the information was very important to them. Focusing on the doctor–patient relationship, Lu [1] found that patients’ eHealth literacy was found to be positively associated with patient adherence through the mediations of physician–patient communication, internet health information-seeking behavior, and perceived quality of internet health information in OHCs [5].

2.4. Hypothesis Development

Rational users in OHC strive to provide and receive quality information to reduce the cost of information search and the uncertainty of misinformation [27]. Nevertheless, the cost of information search and its verification remains high. This is because information about health care requires more accuracy than any other field because the symptoms of a disease can vary depending on the specificity of the individual, and because the information is related to life [5]. For example, even if the information provided by a particular person working in OHC is generally accurate, if the person receiving the information has their own particularities, accepting the information may lead to negative consequences.

This can be explained more specifically through the concept of health literacy. Health literacy is an individual’s ability to understand, process, and acquire basic health information in order to make appropriate health decisions. It refers to the broader ability to seek, understand, evaluate, and use health information to reduce health-related risks and improve quality of life [28]. Therefore, health literacy is an essential skill for consumers to search for, analyze, and effectively utilize information for health care and health information [29]. Health literacy is categorized as (1) Functional health literacy, which relates to basic reading and writing skills to understand and convey simple health messages; (2) Interactional health literacy, which relates to managing health through collaboration with professionals; and (3) Critical health literacy, which relates to critically analyzing information to spot inaccuracies [29]. As such, health literacy does not simply refer to reading comprehension of health information, but to the various ways to interpret, utilize, and communicate health information, as well as the competencies associated with them. However, a lack of these skills can lead to the misinterpretation of information, information overload [30], confusion, and the acceptance or misinterpretation of information [22]. However, it is difficult for users of OHCs to achieve a high level of health literacy all the time, no matter how hard they try [27]. In turn, this means that the more followers there are, the higher the diversity of individual characteristics, which may increase the false note rate of users. Based on the above discussion, we formulate the following hypothesis.

Hypothesis 1 (H1). Indirect online health information activities (i.e., followers) in online health communities increase the false note.

The costs associated with searching for and verifying information are unquestionably negative. Therefore, reducing these social costs is a win–win [16,31]. In this study, indirect online health information activities refer to a user’s number of followers, while direct online health information activities refer to a user’s following behavior, total posts, and most recent activity.

First, there could be direct user efforts. More specifically, by following users who possess high levels of health literacy, they can make efforts to gather information that is different from their own perspective [32], provide more information, and continue to engage with the community. However, given the characteristics of health care, it is very important to look at the indirect efforts of users along with the direct efforts because it involves fitting the individual’s situation more than any other field [33]. For example, quality information provided to consumers through a high level of health literacy secured directly or indirectly is verified by other users. When this process is repeated, it naturally gains many followers.
while eliminating the risk of information searching and verification [34]. However, during this process, continuous communication with followers about the health information provided by the influencer will reduce false notes by identifying individual characteristics and reducing misunderstandings to provide more appropriate information [32]. Existing studies mainly examine the characteristics of OHC users individually, but due to the specificity of medical information, we believe that rational users engage in information search activities to reduce uncertainty in health care decision-making. This study will focus on the interaction of consumers’ direct and indirect information search activities to reduce uncertainty. In particular, engaging in direct online health information activity, including activities such as following other users, posting comments, and recent activity, makes it possible to decrease the number of false notes experienced by users. This direct online health information activity will also have an impact on the number of false notes from users with a large number of followers.

**Hypothesis 2 (H2).** Direct online health information activities (following, total posts, and last activity) in online health communities reduce the number of false notes.

**Hypothesis 3 (H3).** Direct online health information activities (i.e., following, total posts, and last activity) in online health communities moderate the positive relationship between indirect online health information activities and false notes.

Figure 1 presents a graphical representation of all the hypotheses discussed thus far.

![Figure 1. Research framework.](image)

3. Data and Methodology

3.1. Research Context and Sample

OHI has become a significant concern in today’s digital age, where social activities are pivotal in disseminating information. The detrimental effects of health misinformation can lead to uninformed decisions, potential harm to individuals’ health, and an overall decline in public health outcomes. Therefore, understanding the impacts of users’ direct and indirect information search activities on OHI is crucial to develop strategies for improvement. To address this question, the research data were sourced from PatientsLikeMe.com, a popular online platform where patients share their health-related experiences and engage
in social interactions. PatientsLikeMe.com, as a major OHC, provides a supportive space for chronic disease patients to share their daily experiences and information about their illnesses, provide and receive information support, and learn about the disease from other patients [32]. PatientsLikeMe.com has provided a rare opportunity to observe patients’ health information-sharing activities and identify their learnings about the disease from the information-sharing activities [35]. The sample for this study consisted of individuals diagnosed with Type 2 diabetes as their primary condition. Managing Type 2 diabetes involves multiple aspects, such as lifestyle modifications, medication management, and monitoring blood sugar levels. This complexity can make individuals more vulnerable to misinformation, as they may seek information online to better understand and manage their condition. By delving into the effects of health misinformation, we can gain useful knowledge about the potential dangers and outcomes for those with Type 2 diabetes. Data collection spanned one year, in 2018, allowing for a comprehensive analysis of the relationship between social activities and the prevalence of health misinformation within this population. Due to the widespread misinformation surrounding COVID-19, we have chosen to exclude data after 2019.

The primary focus of the study was to measure the prevalence of “false notes” related to complications in diabetes. Following a comprehensive assessment by the medical researcher (G. R.), the remaining researchers (J.Y. Y. and T. R.) sequentially engaged in corroborating the accuracy of the numerical data, and three authors performed cross-checking as the last step. A comprehensive assessment was conducted using various sources to evaluate the accuracy of these claims. Specifically, the claims were compared against the International Classification of Diseases, 10th Edition (ICD10) database, the World Health Organization (WHO) complications lists, and the American Diabetes Association (ADA) complication lists. Each claim was categorized as either correct or incorrect based on the information provided by these authoritative sources. Within the sampling period, we gathered 753,858 users for data using the ARM technique. Some samples were excluded by applying the following criteria: (1) Participants who had not logged into the platform within the specified time frame of 36 weeks were excluded from the study; (2) We have excluded users who have no followers, have never made any helpful remarks, have no posts, and do not follow anyone (this criterion is intended to be combined with simultaneous “and” conditions); and (3) Users who had no followers or followings and did not create posts or provide helpful remarks were excluded. Lastly, a total of 15,141 claims about complications were collected from the valid 6731 users included in the study with a cross-sectional approach.

3.2. Measures

We used the age and last activity to measure the online health community participation and to examine the general impacts of online health community participation on individual knowledge. Age captures the duration of when a user used the online health community. The last activity captures the temporal activeness of a user’s participation in the online health community. Second, we used followers, total posts, and following to delineate the impacts of online health community participation on learning. However, these can have two different conceptual meanings. Total posts and following require the user’s efforts and active behavior on information sharing and learning. More specifically, the user needs to write their own post and upload it for posting. Likewise, the user needs to find another user to follow and a need to ask for the following. All of these require the user’s active participation and effort. In contrast, the follower does not require active participation and effort. It is another user who can follow to be a follower. To investigate the effects of direct and indirect information activity, we distinguish these two categories of activities as illustrated in Figure 1.

In this study, the variables were measured as follows. A false note is referred to as the number of incorrectly claimed complications that users made. This variable captures the count of complications claimed by users evaluated as incorrect based on the comparison
with authoritative sources such as the ICD10 database, WHO complications list, and ADA complication lists. “Follower” represents the number of followers that each user has. It means the count of other users who have chosen to follow a focal user. Total posts are measured as the number of posts each user has made. “Following” is defined as the number of users that each focal user follows. This variable represents the count of other users a focal user has chosen to follow. “Age” represents the age of each focal user. “Last activity” means the minutes elapsed until a user re-logged in within two weeks, and we measure it using the natural logarithm. It measures the duration between a user’s last login and subsequent login within a specific time frame.

3.3. Analysis Methods

The attributes of false notes exhibit a notable tendency towards values close to zero and a high frequency of zero occurrences, indicating an excess of zero values. Due to this characteristic, applying zero-inflated negative binomial regression (ZINB) is deemed efficient. ZINB is specifically designed to model count variables characterized by excessive zeros and is commonly employed for count outcome variables exhibiting overdispersion [36]. Moreover, in principle, the excess zeros are generated through a distinct process separate from the count values, allowing for independent modeling of the excess zeros.

In this study, H1 assumes that the user’s indirect information activity in OHC causes false notes, H2 postulates that direct information activity in OHC reduces false notes, and H3 examines the interaction between H1 and H2. The validation of the moderating effect within this study involved the introduction of an interaction term between indirect and direct information activities into each respective model. To illustrate, the indirect information activity of “follower” was subjected to interaction with the direct information activities of “following,” “total posts,” and “last activity.” The statistical significance of these interaction terms was subsequently established within each model. All variables involved in the analysis were mean-centered to assess the moderating effect. Mean-centering consists of subtracting each variable’s mean value from its data points. By mean-centering the variables, the focus is shifted to the deviation from the mean, allowing for a more accurate examination of the moderating effect within the regression analysis [37]. Statistical analysis was conducted employing STATA version 16.0 [38].

4. Empirical Results

Table 1 displays the descriptive statistics and correlation coefficients among the variables. Most correlation coefficients were below 0.5 and statistically significant at \( p < 0.05 \), indicating meaningful associations between the variables. As anticipated, the mean value of the false note variable was close to zero, indicating that, on average, users did not make false claims about complications; 82% of the observations had a false note value of zero. On average, the user was 58.6 years old, the number of followers was 0.33, the number of total posts was 0.24, and the number of the following was 0.39. The variance inflation factor (VIF) was examined to assess the presence of multicollinearity. The VIF values ranged from a minimum of 1.00 to a maximum of 1.98, all of which were below the threshold of 5. This indicates no substantial risk of multicollinearity among the variables in the regression model [39].

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Std. Dev</th>
<th>Min</th>
<th>Max</th>
<th>VIF</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 False note</td>
<td>0.18</td>
<td>0.98</td>
<td>0</td>
<td>19</td>
<td>1.25</td>
<td>1</td>
<td>1</td>
<td>0.03</td>
<td>1</td>
<td>0.00</td>
<td>1</td>
</tr>
<tr>
<td>2 Age</td>
<td>58.63</td>
<td>9.37</td>
<td>18</td>
<td>110</td>
<td>1.00</td>
<td>−0.03*</td>
<td>1</td>
<td>0.07</td>
<td>0.01</td>
<td>0.05</td>
<td>1</td>
</tr>
<tr>
<td>3 Follower</td>
<td>0.33</td>
<td>2.77</td>
<td>0</td>
<td>117</td>
<td>1.98</td>
<td>0.43 *</td>
<td>0.02</td>
<td>1</td>
<td>0.57</td>
<td>1</td>
<td>0.50</td>
</tr>
<tr>
<td>4 Total posts</td>
<td>0.24</td>
<td>4.94</td>
<td>0</td>
<td>326</td>
<td>1.63</td>
<td>0.17 *</td>
<td>0.03 *</td>
<td>1</td>
<td>0.57 *</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>5 Following</td>
<td>0.39</td>
<td>5.00</td>
<td>0</td>
<td>204</td>
<td>1.51</td>
<td>0.20 *</td>
<td>0.00</td>
<td>0.52</td>
<td>0.50 *</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>6 Last activity</td>
<td>5.01</td>
<td>1.27</td>
<td>0.04</td>
<td>6.59</td>
<td>1.03</td>
<td>−0.07 *</td>
<td>−0.01</td>
<td>−0.08 *</td>
<td>−0.04 *</td>
<td>−0.05 *</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 1. Descriptive statistics and correlations (N = 6731).

Notes: VIF = variance inflation factor, \( * p < 0.05 \).
Table 2 presents the outcomes of ZINB regression, which is aimed at verifying the hypotheses of this study. The analysis revealed that in Model 1, with age included as a control variable, the coefficient for age ($b = -0.011, p > 0.05$) indicated a non-significant effect on the dependent variable, the user’s false note, and incorrectly claimed complications from other users. Model 2, which explores the indirect information search behavior in OHC, provides validation results for Hypothesis 1, stating that the number of followers of a user is positively associated with the occurrence of false notes. The analysis confirmed that this positive relationship was statistically significant, supporting Hypothesis 1 ($b = 0.691, p < 0.001$). Model 3 examines the verification of Hypothesis 2, which suggests that users’ direct OHI behaviors can reduce the occurrence of false notes while controlling for indirect OHI. The analysis revealed that the last activity variable significantly affected false notes ($b = -0.142, p < 0.001$), indicating that users who engaged in more recent direct OHI activities were associated with lower levels of false notes. However, the total posts ($b = -0.009$) and the following ($b = 0.015$) were found to be insignificant, respectively, suggesting that these variables did not significantly impact false notes.

Table 2. Results of zero-inflated negative binomial regression.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
<th>Model 4</th>
<th>Model 5</th>
<th>Model 6</th>
<th>Model 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>$-0.011$</td>
<td>$-0.016$ **</td>
<td>$-0.016$ **</td>
<td>$-0.017$ **</td>
<td>$-0.016$ **</td>
<td>$-0.016$ **</td>
<td>$-0.016$ **</td>
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<tr>
<td></td>
<td>(0.008)</td>
<td>(0.006)</td>
<td>(0.006)</td>
<td>(0.006)</td>
<td>(0.006)</td>
<td>(0.006)</td>
<td>(0.006)</td>
</tr>
<tr>
<td>Follower</td>
<td>0.691 ***</td>
<td>0.313 ***</td>
<td>0.357 ***</td>
<td>0.365 ***</td>
<td>0.148 ***</td>
<td>0.182 ***</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0.059)</td>
<td>(0.065)</td>
<td>(0.067)</td>
<td>(0.071)</td>
<td>(0.026)</td>
<td>(0.033)</td>
<td></td>
</tr>
<tr>
<td>Total posts</td>
<td>$-0.009$</td>
<td>0.021</td>
<td>0.050</td>
<td>$-0.010$</td>
<td>0.031</td>
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<td></td>
<td>(0.018)</td>
<td>(0.016)</td>
<td>(0.034)</td>
<td>(0.018)</td>
<td>(0.031)</td>
<td></td>
<td></td>
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<tr>
<td>Following</td>
<td>0.015</td>
<td>0.064 **</td>
<td>0.019</td>
<td>0.006</td>
<td>0.043 *</td>
<td></td>
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<tr>
<td></td>
<td>(0.016)</td>
<td>(0.021)</td>
<td>(0.017)</td>
<td>(0.014)</td>
<td>(0.021)</td>
<td></td>
<td></td>
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<tr>
<td>Last activity</td>
<td>$-0.142$ ***</td>
<td>$-0.139$ ***</td>
<td>$-0.137$ **</td>
<td>$-0.225$ ***</td>
<td>$-0.206$ ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0.042)</td>
<td>(0.041)</td>
<td>(0.042)</td>
<td>(0.039)</td>
<td>(0.040)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follower × Following</td>
<td>$-0.003$ ***</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td>(0.001)</td>
<td></td>
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<td></td>
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<tr>
<td>Follower × Total posts</td>
<td>$-0.002$ ***</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td>(0.000)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follower × Last activity</td>
<td>0.006 ***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0.010)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Constant</td>
<td>$-0.856$</td>
<td>$-1.440$ ***</td>
<td>0.324</td>
<td>0.165</td>
<td>0.645</td>
<td>0.191</td>
<td>0.445</td>
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<tr>
<td></td>
<td>(0.463)</td>
<td>(0.327)</td>
<td>(0.442)</td>
<td>(0.445)</td>
<td>(0.434)</td>
<td>(0.434)</td>
<td>(0.425)</td>
</tr>
<tr>
<td>N</td>
<td>6731</td>
<td>6731</td>
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<tr>
<td>AIC</td>
<td>5169.824</td>
<td>4840.811</td>
<td>4807.470</td>
<td>4787.587</td>
<td>4760.972</td>
<td>4767.104</td>
<td>4750.096</td>
</tr>
<tr>
<td>BIC</td>
<td>5203.896</td>
<td>4881.698</td>
<td>4868.799</td>
<td>4855.730</td>
<td>4829.115</td>
<td>4835.247</td>
<td>4831.868</td>
</tr>
</tbody>
</table>

Notes: Standard errors in parentheses, AIC = Akaike information criterion, BIC = Bayesian information criterion, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Models 4–6 investigated whether direct OHI behaviors moderate the positive relationship between indirect OHI behaviors and the user’s false note. These models aimed to examine the significance of the interaction effect between direct OHI behaviors and indirect OHI behaviors while controlling for relevant variables. In Model 4, the analysis investigated the interaction effect of the number of followers and the number of following on the false note. The result indicated that the interaction effect was statistically significant ($b = -0.003, p < 0.001$). In Model 5, the analysis assessed the interaction effect between the number of followers and the total number of posts on the false note. The results revealed that the interaction effect was statistically significant ($b = -0.002, p < 0.001$). In Model 6, the analysis analyzed the interaction effect between the number of followers and the last activity on the false note. The results indicated that the interaction effect was statistically significant ($b = 0.064, p < 0.001$). Model 7 inspected the relationship between the dependent variable and all the control, independent, and interaction terms used in the previous models.
longer present in Model 7 ($b = -0.000, p > 0.05$). However, the coefficient direction and significance of the remaining variables were maintained. This suggests that the overall relationships and patterns observed in the previous models largely persisted in Model 7.

To provide a more concrete breakdown of the moderating effect, the researchers plotted the moderating effect using one standard deviation below ($-1SD$), above ($+1SD$), and the mean of each direct activity of OHI (i.e., following, total posts, and last activity). These plots illustrate how the interaction between the independent and moderating variables affects the dependent variable at different levels of the moderator variables. According to Models 4 through 6, Figure 2a–c display these plots, highlighting the moderating effect and its variation across three levels. By comparing the significance of the interaction terms and observing the patterns depicted in the figures, it was confirmed that all moderating effects were verified. Based on these findings, we can conclude that Hypothesis 3, which posits the presence of moderating effects, is supported. The results indicate that the relationship between direct OHI behavior, the number of followers, and false notes are influenced by the interaction between these variables, further emphasizing the importance of direct OHI behavior in softening false claims. Taking into consideration the loss of significance in the interaction term between followers and total posts in Model 7 compared with Model 5, it is appropriate to conclude that Hypothesis 3 is partially supported.

![Figure 2. Moderation effect of (a) Following; (b) Total posts; and (c) Last activity on the relationship between followers and false note.](image-url)
Although beyond the scope of the current study, a robustness check was conducted by changing the dependent variable from false notes to total complaints. This additional analysis aimed to ensure the reliability and consistency of the findings. Using ZINB regression, the results confirmed that the same directionality and significance observed in the original analysis were maintained. This suggests that the findings are robust and consistent across different dependent variables, further strengthening the validity of the study’s conclusions.

5. Discussion and Implications

5.1. Discussion

The potential exists for the impact of users’ direct and indirect information activities within OHC on the occurrence of false notes to undergo temporal fluctuations. There are many reasons why this could happen, such as changes in how people use the platform, shifts in the way the community interacts, updates to how information is shared, and differences in engagement levels over time. First, the influence of direct and indirect information activities might exhibit distinct trajectories as users become acclimated to the community environment. Over time, users may adjust their preferences for engagement, potentially leading to shifts in the relative significance of these activities in contributing to false notes. The interplay between different types of activities and their impact on false notes could be influenced by various factors like the emergence of new norms, changes in the prevalence of misinformation, or the evolution of community guidelines. Second, user expertise and familiarity with the OHC could evolve, altering how they discern and interact with information. As users become more experienced, the effectiveness of their direct and indirect activities in mitigating false notes might change due to refined information evaluation skills or a deeper understanding of community dynamics. Third, changes in the composition of the user base or fluctuations in community trends could influence the reach and propagation of information, potentially impacting how direct and indirect activities contribute to false notes. The influence of network effects and social interactions within the community might also contribute to shifts in the effectiveness of different activities over time.

Additionally, the impact of direct and indirect information actions carried out by active users in OHCs may vary depending on the type of OHC. This phenomenon can be attributed to several nuanced factors inherent to the distinct nature and purpose of various OHCs. Different OHC types may cultivate unique norms, communication styles, and information dissemination practices. Consequently, the impact of direct and indirect information activities on the occurrence of false notes may vary based on how well these activities align with the prevailing dynamics of a particular OHC type. For instance, in specialized medical OHCs where accurate and technical information is highly valued, direct information activities—involving the provision of factual and evidence-based insights—may be particularly effective in reducing false notes. Conversely, in more open-ended or support-oriented OHCs, indirect information activities such as sharing personal experiences and opinions might be more influential in shaping the discourse. In essence, the heterogeneous landscape of OHC types implies that the interplay between direct and indirect user activities and the occurrence of false notes is contingent upon the specific context, purpose, and dynamics of each OHC type.

Finally, the analysis findings reveal a significant correlation between age and the most recent activity with a reduced incidence of false notes. Conversely, statistical significance was not observed in the associations between the aggregate count of posts and followers vis-à-vis the frequency of false notes (see Model 3). This suggests that user engagement activities predominantly centered around perusing others’ posts, as opposed to active contributions or following fellow users, may hold substantial importance in acquiring knowledge concerning complications related to diabetes. This discernment could potentially stem from the fact that a substantial portion of the posts, authored by individuals without formal healthcare training, may exhibit inaccuracies. Consequently, attentive and
critical engagement might be requisite to glean accurate insights from such content. In this vein, the preference for reading and evaluating content rather than direct participation could emerge as a discerning strategy for enhancing knowledge acquisition within the context of diabetes complications.

5.2. Theoretical Implications

This study makes theoretical contributions in two key areas. First, our empirical study contributes to the existing literature on information-exchange behavior. With many consumers routinely seeking health information online [10,11], several studies have been concerned about the uncertainty and low reliability that characterize OHI [40,41]. However, there is a lack of quantitative research to support these arguments, and even less consideration of variables that can improve uncertainty and low reliability [14]. This research study utilizes a quantitative methodology, which has been lacking in previous investigations focusing on OHI. To achieve our research objectives, we enhance and expand upon existing research by categorizing the activities within OHI as either indirect or direct and examining the impact of each search activity on the occurrence of false notes. Additionally, we explore the interactions between these activities. Furthermore, we conducted additional robustness checks to demonstrate the consistency and validity of our findings across various dependent variables.

Second, this study contributes to identifying factors that influence rational behavior among users by considering OHC as the primary platform where OHI is most actively conducted, drawing insights from decision-making literature about information search [2]. Through an analysis of user data obtained from PatientsLikeMe, our findings indicate a correlation between the number of followers a user possesses and the occurrence of false notes within OHCs. Furthermore, we observed that the direct OHI activity influenced false notes, wherein users who recently engaged in direct OHI activity exhibited a lower incidence of false notes. Conversely, the total number of posts and the number of users followed were statistically insignificant, suggesting that these particular variables do not significantly impact the occurrence of false notes. Subsequently, we investigated whether direct OHI behaviors function as moderators in the positive relationship between indirect OHI behaviors and users’ false notes. Our results reveal a statistically significant interaction effect, underscoring the significance of direct OHI behaviors, such as a following, total posts, and last activity, in moderating the occurrence of false notes among users.

5.3. Managerial Implications

This research has a number of practical implications for reducing uncertainty in OHI by lowering the cost of information discovery and information verification for users exchanging information through OHC. Our work fleshes out existing discussions in OHI research. Our research started with a very simple problem statement: How can we reduce the social costs of information discovery and verification in OHI? A common implication of existing research on this issue is that (1) Unlike information about common consumer goods, health care information requires a relatively high level of complexity and expertise [6]; and (2) Consumers have different physical characteristics and varying levels of health literacy [42], and even the same information can be received in different ways [27], which implies the importance of interaction between information providers and information seekers. In this study, we examined users’ information provision and acquisition activities in OHCs by categorizing them into indirect and direct OHI activities (i.e., following, total number of posts, and last activity).

Our results showed that the higher the number of followers a user has, the higher the number of false notes, but that users with more recent direct OHI activity have fewer false notes. On the other hand, a following, total posts, and last activity all moderated the effect of higher followers on false notes. In general, having a large number of followers is considered to be a sign of trustworthiness, but the opposite result can be explained by the aforementioned reasons for not improving the trustworthiness of OHI information.
Therefore, to improve the trustworthiness of OHI, it is most important to increase the frequency of users’ recent OHI activity, i.e., to increase users’ engagement. The implication for OHC operators in this study is that it is important to increase the frequency of users’ access to OHI in order to improve the reliability of OHI because higher engagement increases the likelihood of resolving personal fits and misunderstandings by increasing the frequency of communication between users. It also suggests that for users of OHCs, interaction rather than one-way provision and acquisition of information is most important.

5.4. Conclusions

Research on user behavior in OHI in OHC can contribute to several United Nations Sustainable Development Goals (UNSDGs). First, by studying user behavior in OHI within OHC, we can gain insights into how individuals from different socio-economic backgrounds access and utilize health-related information (SDG Goal 1). This understanding can help us identify barriers that prevent impoverished people from accessing crucial health information. Through targeted interventions and an improved dissemination of OHI, we can empower marginalized communities with the knowledge needed to make informed health decisions, ultimately helping to break the cycle of poverty and improving their overall well-being. Second, research on user behavior in OHI and OHC can improve health literacy and increase awareness of health-related issues (SDG Goal 3). When individuals can access accurate and reliable health information, they are better equipped to make informed decisions about their health and well-being. This can lead to better preventive practices, early detection of health problems, and improved management of chronic conditions. By promoting active participation and engagement in OHCs, individuals can receive peer support and connect with others facing similar health challenges, fostering a sense of belonging and improving mental well-being. Third, OHI and OHC platforms can serve as equalizers by providing a space where individuals from diverse backgrounds can access and share health information, experiences, and resources (SDG Goal 10). Research on user behavior can help identify potential disparities in access, participation, and engagement within these platforms. By understanding these inequalities, interventions can be designed to ensure that marginalized and underserved populations have equal access to OHI and OHCs. Additionally, by facilitating interactions and discussions among individuals with varying levels of health expertise and experiences, OHCs can promote mutual learning and reduce information disparities, reducing inequality in health knowledge and outcomes.

5.5. Limitations and Directions for Future Research

It is important to acknowledge certain limitations of our study. Firstly, the data used in our study were obtained solely from PatientsLikeMe, which may not capture the entire population of OHC users and could have restricted generalizability. Secondly, the study focused specifically on users who self-reported having Type 2 diabetes, thus limiting the findings to other health conditions within OHCs. Furthermore, the study primarily examined the risk of encountering incorrect information within OHCs and did not delve into the underlying reasons or motivations behind disseminating false notes. Lastly, the findings are based on cross-sectional data, limiting our ability to establish causal relationships between variables. These limitations should be considered when interpreting our study’s results.


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