Why Do Older Adults with Type 2 Diabetes Join a Diabetes Online Community?

Abstract

Objective: As individuals age, chronic health difficulties may disrupt physical and social well-being. Individuals can turn to online communities to interact with similar peers, which may help buffer negative effects resulting from health difficulties. However, because the specific resources sought remain unclear, the present study investigated the reasons that older adults join a Diabetes Online Community (DOC).

Method: We used semantic network analyses to categorize the reasons participants provided for joining during the sign-up process. Results: The most frequent reasons for joining were: to seek information about their health condition, to help with self-management of health difficulties, for feelings of informational and social support, and for having a community with whom to share. Women were more likely to go online for sharing/companionship and information/social support reasons, whereas men were more likely to go online for general information and self-management reasons. Conclusion: This study shows the reasons individuals seek to join a DOC, for increased information and support regarding chronic health difficulties. Practice Implications: Practitioners may want to consider ways to promote access to online communities among their older patients as a source of health information and a resource to provide a sense of community.

Keywords: online community, diabetes, health information, health support, chronic health difficulty; self-management

Introduction

Across the lifespan social interactions with same-aged peers, who are more likely to share attitudes, values, and interests, are important [1]. But mobility barriers, because of health difficulties may limit social contact [2 3]. Online communities, defined as collectives of voluntary members who share common interests or experiences, and interact primarily over the Internet [4], may offer older adults, or people over age 65, an opportunity to engage with peers regardless of physical ability and location [3]. Online communities specifically for older adults are steadily growing [3], as increasing numbers of older adults have broadband access, use smart phones and are becoming active in using the Internet [5] at the fastest rate of any population [6]. The potential for older adults to benefit from the internet for health information seeking [7 8], managing chronic conditions [7 9 10], interacting with similar peers [3], and engaging in online communities is beginning to be recognized [11 12]. However, relatively less attention has been paid to understanding older adults' perceived benefits of joining online health communities and few if any studies have directly examined older adults' reasons for joining online communities.

In the present study, we examined reasons older adults provided for joining an online community during their initial registration, to shed light on their needs and goals. The socioemotional selectivity theory suggests that older adults, due to perceived limitations on time and energy, are more likely to invest time maintaining quality social connections and balancing health states relative to forming new relationships and seeking new information [13]. However, it is unclear whether this distinction holds for online
communication that removes physical barriers, potentially making it easier to interact, and for topics that are highly self-relevant such as those pertaining to one's health condition [14]. Thus, older adults' motivation for joining online communities may involve both forming new relationships and seeking information. Previous studies have shown that online communities may provide a space for older adults to seek health information, self-management strategies, and peer support and interaction [3 15 16]. We add to this literature by identifying reasons older adults provided when joining an online community.

Health information seeking
Although older adults receive health information from their primary care providers, seeking supplementary health information is still one of the most popular online activities [6], especially if the information given by health professionals is difficult to understand [9]. Some members of online communities report healthcare providers as the primary source of information [17], but participation in online communities can supplement that information through observing and interacting with individuals who have similar health conditions [9]. Older adults may find that health information in online communities differs from that of general websites, because the information shared in online communities is often tailored to the unique needs of the group, and the information may be more acceptable to receive from people with similar needs or goals [15]. The information may also be easier to understand, based on their social connections' recent experience, and readily available content [14].

Moreover, an online environment allows older adults to send and receive information to and from others asynchronously, thus reducing any restriction on time and mobility for receiving information about their condition [14] which may increase a sense of control [18]. In light of these findings, as well as research suggesting that gathering general information regarding chronic health conditions is a key reason that older adults go online [19-22], we expect to find that a one reason older adults join online health communities is to obtain general information.

Self-regulation and management
More specifically, however, older adults likely join online communities to seek information related to self-management of a chronic health condition, which has been shown to contribute to older adults' quality of life [21 23-25]. During times when primary providers are unavailable, older adults may need guidance in self-management of their health condition and may turn to the online community to receive that support [3 9]. People tend to trust others with shared experiences; the information shared in online communities may positively influence health behaviors [9]. One example would be community members co-constructing health knowledge and working together to fill gaps in health information to better understand their condition [3 26]. Therefore, we expect that another reason individuals will list for going to the online community may be related to seeking self-management information.

Peer and Social Support
In addition to being a valuable resource for seeking health information, social support for chronic health difficulties may be another reason for joining an online communities [27]. Receiving social support is particularly important for an individuals' well-being, by reducing stress and increasing adherence to treatment plans [15]. Low social connectedness is consistently associated with poorer health outcomes [28 29], and so those interacting in online communities may have more assistance in monitoring their condition and have a greater pool of self-management support resources [30 31].
Social support is especially valued when it comes from individuals with similar experiences [32]. A crucial benefit of online communities is that self-disclosure about chronic health conditions is perceived to be easier than in face-to-face discussion [3]. Allowing one to see their experiences as normal and receive praise for successful self-management, as well the confidence boost to reveal certain experiences to their provider is also an advantage [14]. In fact, greater social involvement online may lead to better self-management, physical health, and emotional well-being [9 28]. Although participation in online communities may not cure chronic health difficulties, the support from social connections may help improve the quality of life for older adults [27], thus it is essential to thoroughly understand the types of support being shared and received in online health communities. As previous studies have shown, individuals often go online to receive support for the information received from providers [19 21 22 33] and to receive social support to reduce adjustment difficulties that often coincide with chronic health difficulties [34-38]. Therefore, we expect individuals going to online communities for support will identify and cite reasons related to (1) information seeking and (2) to maintain contact with similar peers.

The present study
In the present study, we investigated three general areas, health information seeking, self-regulation, and social support, that older adults may offer as reasons they joined an online health community. We drew on data from one of the largest diabetes online communities (DOC) in the US, the Diabetes Hands Foundation (DHF). The DHF was a nonprofit organization that "connects, engages and empowers people touched by diabetes." As of this printing the DHF has resolved and TuDiabetes is now part of the Beyond Type I organization. Leaders of DHF provided a de-identified dataset of the initial registration information collected when a new member joined the English-speaking language community (TuDiabetes.org). Based on literature reviewed above, we used semantic network analyses to confirm and further refine the reasons given for joining the DOC in the areas of information-seeking, advice on self-management, and to maintain peer connections and receive support from peers.

Methods
The dataset included limited demographic information including age, sex, and diabetes type (I or II). The reason for joining was obtained from an open-ended question, “Why did you want to join?” Permission for this study was obtained from the Institutional Review Board at a northwestern university.

Inclusion criteria for the study were that member had to be at least 65 years old and have type II diabetes. The database contained 34,797 records, 30,248 participants were younger than 65 years old; 435 had type I diabetes; 49 had Pre/No Diabetes, and 2,096 did not specify their age. The final sample included 1,969 individuals, ages 65 and over, with type II diabetes.

Procedure
We analyzed the unstructured free-text field responses that members provided upon joining in two phases:

Phase I
First, we examined the content of each response using semantic network analysis, which assesses the frequency of word co-occurrences [39]. The more frequently two words co-occur, the more strongly they are related (as reflected in the pair’s “weight”). Centrality of a word, or the amount of connections any
word has with all other words, was also measured to reveal the importance of a concept in the dataset used ("weighted degree"). This approach has the added benefit of allowing us to produce a visual representation of the relationships among the concepts. We used ConText, which was created to conduct text and network analysis in an automated fashion for researchers in the digital humanities and social sciences [40], to construct the semantic network matrices, using the top 100 word-pairs (co-occurrences of the words). To test inter-coder reliability, a sub-sample of at least ten percent of the full sample is required to be coded independently by independent coders [41]. In this study, a sub-sample of the top 26.5% word-pairs (weight of 7,077 out of 26,685), or the top 100 word-pairs, each with a weight 25 or more, were coded by three independent coders. A weight below 25 meant that the word pair had occurred less than 0.1% (25 out of 26,685) of the time, rendering those word pairs less significant. We then imported the top 100 word-pairs into Gephi, a software for graph and network analysis that displays large networks for interactive exploration [42] and UCINET, similar to Gephi is used for graphical representation of network analysis [43] to run the matrix files in order to display the graphs, and calculate each word’s centrality. This provided us with information on the connections among concepts within each open-ended response, and therefore, we referred to this as an item-analysis.

The output of the network analysis can be seen in Figure A.1 (for all pairs) and Figure A.2 (top weights only). The strength of the relationship between word-pairs is denoted by line thickness. For example, the word-pair “Diabetes information” (485) co-occurred most frequently, signified by the thickest line in Figure A.2. Each of the top 12-word pairs (diabetes-information, support-information, help-information, learn-information, other-information, more-information, share-information, how-information, control-information, knowledge-information, learn-diabetes, and information-sharing) were related to sharing of information, giving an aggregated weight of 2,762, out of 7,077, which is approximately 39% of the top 100 pairs.

**Phase II**

Borrowing the approach used by Wang and associates [44] and taking into account the output from the semantic network analysis (Phase I), we identified broad categories into which the word pairs could be coded. We established the broad categories to provide an orienting framework to organize the word pairs, in order to have a way to consistently categorize the common ways in which individuals use the DHF. We coded pairs (Table A.1) as general information, self-management, share/support/companionship, informational support, and social support. Pairs were coded as general information if they indicated that the new member sought advice, referrals, or knowledge [19 21 33]; self-management if the word pairs indicated older adults going to the DHF for help with activities such as diet, self-regulation, pump, or medicine [23-25]; share/support/companionship if the word pairs indicated anything involving two or more people and do not include words such as support, help, or advice [25 34 35]; informational support if the word pairs were informational in nature and included words such as support, help, or advice while mentioning another person [34 35 45]; and social support if the word pairs were social in nature and included words such as support, help, or advice while mentioning another person [34 35 45].

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Definitions of the coded categories and word-pair examples.</th>
</tr>
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<tbody>
<tr>
<td><strong>Category</strong></td>
<td><strong>Definition</strong></td>
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We coded the top 100 word-pairs (with a weight of 7,077, out of a total weight of 26,685) to determine their relative frequency. Word-pairs were coded independently by two raters, yielding adequate reliability (Cohen’s Kappa = .73); a third rater resolved disagreements.

In sum, we conducted two sets of analyses, item-level and person-level, on these words used by older adults. Item-level analyses were conducted to assess the frequency of word co-occurrences. Person-level analyses were conducted to examine possible individuals’ differences in reasons for joining the DHF. Word pairs were always coded into the most specific categories if possible (self-management, share/support/companionship, informational support, social support); if word pairs could not be coded into the specific categories but were informational in nature, we coded them as general information. Less than 2% of the word pairs could not be coded into a category.

Results
Item analyses (Figure A.3) showed that, among the most highly weighted 100 word-pairs (i.e., those having weight of 25 or more), 45.54% reflected general information seeking. However, slightly more than half of the pairs fell into more specific categories. Specifically, 13.86% of the word pairs belonged to share/support/companionship, 16.83% were categorized as expressing a desire for self-management...
(including medicine and pump), and 15.84% and 5.94% indicated informational support and social support, respectively. Only 1.99% of the word pairs did not fall into one of our categories (see Figure 3).

Person-level results are shown in Figure A.4. We found that 29.20% (574 members) indicated that they joined the DHF to seek information but provided no additional information; On the other hand, the vast majority of new members provided information that could be more specifically coded. A large proportion of individuals, 18.10% (356 members), stated that they joined the DHF for sharing/support/companionship purposes; 18.50% (365 members) for information related to self-management (including pump and medication); 7.90% (155 members) for informational “support” alone; 5.60% (111 members) for social “support” alone; 3.65% (72 visitors) gave responses that were not applicable; and 17.05% (336 members) did not give an answer.

In addition to examining the percentage of older adults that endorsed the five categories or reasons for going online and interacting within the DHF, we also were interested in exploring whether older adult men and women in this sample differ in the rates that they endorse their respective reasons for joining the DHF. A chi-square test was run to determine whether men and women in this sample endorsed the reasons for joining the DHF at similar rates. Older adult men and women did not endorse each of the five reasons for joining the DHF at the same rates, $X^2 (4, N = 1559) = 16.172, p = .003$. As seen in Table A.2, more men than women older adults in this sample endorsed the general information (41% men vs. 33% women) and self-management categories (24% men vs. 23%), whereas more older adult women than men endorsed the share/support/companionship (24% men vs. 23%), whereas more older adult women than men endorsed the share/support/companionship (21% men vs. 24% women), information support (8% men vs. 12% women), and social support categories (6% men vs. 8% women).

Table 2
Crosstabulation of gender by category

<table>
<thead>
<tr>
<th>Category</th>
<th>Men</th>
<th>Women</th>
<th>$X^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Information</td>
<td>323</td>
<td>251</td>
<td>16.172**</td>
</tr>
<tr>
<td>(41%)</td>
<td>(33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Management</td>
<td>186</td>
<td>179</td>
<td></td>
</tr>
<tr>
<td>(24%)</td>
<td>(23%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Share/Support/Companionship</td>
<td>168</td>
<td>188</td>
<td></td>
</tr>
<tr>
<td>(21%)</td>
<td>(24%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information Support</td>
<td>64</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>(8%)</td>
<td>(12%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>48</td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>(6%)</td>
<td>(8%)</td>
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Notes.
The total N for this sample is 1559 (789 men, 770 women).
* $p \leq .05$, ** $p \leq .01$, *** $p \leq .001$.

Discussion
Even with barriers to social contact in older age such as limitations on mobility as the result of health difficulties, online communities may be one way for individuals to engage with social contact regardless of time, location, or physical ability [2 3]. Engaging with peers online may be of particular importance as individuals, especially those experiencing chronic health difficulties, have increasing need for information
related to prevention, diagnosis, and treatment, and online communication may offer a viable option for dispersing information related to condition management [3 9]. In fact, the study’s results are in line with previous findings that older adults seek information online [6 14]. Not all individuals in this study who used the online community specified the type of information they sought; however, among those who did, there were several reasons: to seek information about their health condition, to help with self-management of health difficulties, for feelings of informational and social support, and for having a community with whom to share.

The results from this study add to the literature in a several ways. First, previous studies have shown that older adults will use online communities to obtain health information related to chronic conditions [6 14]. In order to understand diabetes patients’ use of online resources to seek health information, prior studies have frequently employed interviews [46-48] and surveys [49 50]. Even in situations where they used content analysis, researchers performed only traditional quantitative content analysis [12]. Supplementing traditional quantitative content analysis with semantic network analysis as the current study did, allows for examining users’ online information seeking behavior from a macro perspective. This method can reveal the relations among different words. In the present study, we were able to more precisely specify, that for diabetes, older adults are motivated by the goal of obtaining information about medication and other self-management procedures. Additionally, previous studies have shown that having an online community of similar others may contribute to feelings of support for older adults [15 27].

Our findings add to the literature by showing that older adults hope to gain support, both informational and social. A particularly exciting finding is that the older adults in this sample indicate they are going to the online community for sharing and community purposes, suggesting that in addition to being a health information source, online communities may be one way in which older adults are able to maintain feelings of community with similar others. Interestingly, it may be the case that older adult men and women endorse the reasons for going to the online at different rates. Our exploratory analyses show that men were more likely than women to provide reasons related to general information and self-management, whereas women were more likely to provide reasons related to sharing/support/companionship, information support, and social support. These results may suggest that men are more likely to gather information to help manage a chronic health condition, while older adult women may be more likely to maintaining a sense of community or support in the midst of a chronic health condition. Future studies should further examine differences between older adult men and women, as they may be able to provide support to show consistent or systematic differences in the reasons that older adult men and women join online communities.

The results of this study do not appear to fully support the Socioemotional Selectivity Theory [13], in that older adults in this study appeared to be motivated by obtaining information and by forming new social ties, rather than motivated by maintaining quality social connections and balancing health states. It could be that online health communities provide an exception to the theory because it is relatively easier to form relations and gain information online without limitations on mobility, and because health information is critical to well-being. It remains unclear, however, whether relations are maintained over time through these communities. A theory that might help to explain our results, though, and that may be especially applicable when thinking about online communication or joining online communities is the Motivational Theory of Lifespan Development. This theory suggests that when individuals age, primary control, or the ability to influence environmental outcomes declines, increasing the need for secondary control strategies to maintain capacity for pursuing adaptive goals [51]. It could be that older adults’ use of online communities offer a new type of secondary control strategy for older adults with chronic illness, one that helps them maintain striving for their primary goals related to health and social contact.
Conclusion
In general, the data show that both information and social support are key reasons why older adults join online health communities. More work is needed to examine the interactions between obtaining and using health information on the one hand and feeling socially connected to similar peers on the other. Past work has shown that high levels of DOC engagement is associated with better glycemic levels, diabetes self-care and health related quality of life [52]. The role of peer relationships in online communities remains a key question for future research.

There are several limitations of the current study. First, we relied on naturalistic dataset with an open-ended question on reasons for joining that was likely interpreted differently across individuals and that did not provide an opportunity for follow up questions when general responses were provided. In addition, we do not have information on continued use of the online community or on community members' income or education levels, both of which are related to online use [3]. Still, the dataset provided rich insight into the reasons why older adults joined a well-known online health community.

Practice Implications
The results suggest that older adults seek online communities for specific types of information regarding their chronic health conditions. As such, when designing an online community for use by older adults, it should be created so that it is easy for individuals to seek information from and share information with similar others, especially as it relates to medications and other self-management practices (technology tools). In addition, the results show that older adults seek online communities for social support. While older adults may be given a good deal of health information from their primary care provider, they may find it useful to connect with similar others to better understanding the information and how to apply it to their condition [9 16 17]. Thus, online communities should be designed for sharing and community purposes, so each becomes a place to gain and/or maintain social contact with similar others [47].

Acknowledgments
We would like to thank the Diabetes Hands Foundation and their community of persons living with diabetes for sharing their data with us. This work was supported by the National Science Foundation [NSF GRFP 1650042]. JAL participated in interpreting the analyses and drafted the initial manuscript and revisions. PG conceived of the initial idea for the study, gained access to a dataset, participated in performing and interpreting the analyses, and helped develop the manuscript. CH participated in performing and interpreting the analyses and helped draft the Methods and Results sections. LM conceived of the initial idea for the study, participated in performing and interpreting the analyses, and helped develop the manuscript and subsequent revisions. All authors read and approved the final copy.

Conflict of Interest
None declared

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