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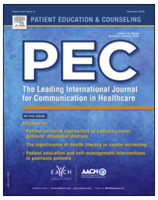

Research paper

The diabetes online community: Older adults supporting self-care through peer health

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A B S T R A C T

Objective: The use of the diabetes online community (DOC) is growing across all age groups. The aim of this exploratory study was to describe why older adults participated in the DOC, and how DOC users interacted with their healthcare providers.
Methods: Telephone interviews (N = 20) were conducted with older adult DOC users (born between 1946 and 1964) living in the United States. Interviews were analyzed using qualitative content analysis adhering to rigor and reproducibility standards.
Results: Themes that emerged from the data related to DOC participation included: information to improve self-care, emotional support, belonging to a community, validation of information, cause for concern and interaction with healthcare providers. Participants used the DOC for day to day diabetes management advice and healthcare providers for medical information and care.
Conclusion: Participants highly valued the DOC and regarded their participation as a way to increase knowledge to improve self-care and reciprocate emotional support with others for diabetes management. The DOC filled gaps in knowledge and support participants were not able to get elsewhere.
Practice implications: The DOC serves as an important source of information and support for individuals with diabetes and may be a cost-effective strategy to augment standard diabetes care.

1. Introduction

Diabetes is a complex chronic condition that requires ongoing attention to day-to-day activities in order to achieve adequate glucose management. It is estimated that recommended diabetes self-care behaviors take more than 2 h per day [1]. The time and intensity spent thinking about the complexities of diabetes and the unavoidable health fluctuations associated can be physically and emotionally taxing. Informational and emotional support is imperative for patients to effectively manage their diabetes [2–4].

1.1. Peer health

Peer health, defined as the interaction, education, and support offered by peers with the same condition to promote health-enhancing change, is gaining traction in chronic disease management, such as diabetes. Core functions of peer groups include supporting day-to-day chronic disease management, encouraging appropriate clinical care, and ongoing social and emotional support [5–7]. Peer interactions between individuals with diabetes provide informational support, emotional support, and mutual reciprocity, which leads to improved diabetes attitudes, diabetes self-care and glycemic levels [8]. Diabetes programs where peers have been trained to be peer health "coaches" or "advisors", coupled with a healthcare provider (HCP) as moderator, has resulted in increased knowledge [10,11], increased social support [8] and improved hemoglobin A1C [8,10–17]. However, peer health may not be helpful for all individuals with diabetes [18] and a secondary factor that unites peers, such as gender, culture, age, or shared experience [8] may be necessary for optimal outcomes.

Online health communities are one format of peer health, allowing individuals to seek information and interact with others for information and support. One example of a diabetes online community (DOC) includes #DSMA (Diabetes Social Media Advocacy), a weekly tweet chat that has been ongoing since 2010 with participation from all stakeholders in diabetes care. With the growing use of online communities, coupled with the aging population, it is inevitable that there will be a population of older adults with health-related online community experience. However, we don't understand how adults anticipate they will continue to use online communities as they age.

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Individuals with diabetes engage in peer health to crowd source the collective wisdom of others to obtain trustworthy and credible information [19] as detailed in Apomediation Theory 19,20]. Apomediation Theory proposes three ways to obtain trustworthy and credible health information: 1) intermediation (HCPs provide information to the patient), 2) disintermediation (HCP is bypassed, patients seek health information directly online), and 3) apomediation (peers lead patients to information). Intermediaries direct, while disintermediaries inform without individualizing information, leaving patients to decipher what is credible and pertinent to their situation. Conversely, apomediaries guide individuals to relevant and credible health information through the collaboration of peers who have produced opinions based on experience [19,20].

1.2. Older adults, diabetes, and social networking

The prevalence of diabetes is increasing among older adults [21,22]. While Internet use may differ among generations, there are few differences in online health information seeking behaviors [23]. Older adults are rapidly adapting social networking [24] and diabetes management tools that are able to complement care among this age group needs further exploration.

Despite the growing reach of the DOC, there is limited research about the DOC and its users. The purpose of this study was two-fold, to describe: 1) why older adult (defined as Baby Boomers born between 1946 and 1964) DOC users participated in the DOC, and 2) how older adult DOC users interacted with their HCPs.

2. Methods

2.1. Sample and recruitment

The study was approved by the University of Utah Institutional Review Board and the administration team from 2 diabetes-specific social media sites in which participants were recruited. Facebook and Twitter were also used to recruit participants. A convenience sample of 76 older adult participants (born between 1946 and 1964) were invited to participate in the study. Potential participants were provided with written information about this study and a telephone interview was scheduled. At the beginning of the call, the interviewer reviewed the study and stated that the interview would be recorded; those willing to participate gave verbal informed consent.

2.2. Interview

A semi-structured interview guide (see Appendix A) was created using a review of literature, input by the research team, and concepts (intermediation, disintermdiation, and apomediation) from Apomediation Theory [19,20]. All interviews were audio-recorded. The interview recordings were transcribed verbatim and transcripts were verified for accuracy by one of the researchers listening to the recordings while reading the transcripts.

2.3. Analysis

A qualitative content analysis was used to analyze the data. This approach to analysis uses a consistent set of codes to organize similar data [25]. The coding template was created after reading the first three transcripts along with the interview guide to generate the initial coding template by one of the investigators (ML). Another investigator (ER) reviewed the codes and coded data to establish credibility that the codes represented the participants own words as closely as possible. The codes were then systematically applied to all of the transcripts with an option for open coding to capture any additional codes that may have been missed with the initial development of the codebook [25,26]. To address dependability, an audit trail was created storing all codes and coded data in a matrix [27]. This allowed reviewing, verifying, and auditing of the coding schema and associated data by the co-authors prior to the analysis. Trustworthiness and rigor were further addressed through methods of reflexivity [28] in which our personal beliefs, assumptions, and roles were continually discussed by the team during analysis to prevent premature interpretations of the data and to recognize assumptions [27–29]. The data were then used to develop corresponding themes [30]. The frequency of codes was not used to assess data saturation but rather the content of the data [31]. Repetitive data emerged, and no new codes emerged by the 14th interview indicating data saturation. However, data from all respondents in the 20 interviews were included.

3. Results

Twenty-two eligible participants agreed to be contacted for an interview. Interviews lasted an average of 76 min. Two interviewed participants lived outside of the United States and were not included in this analysis. Participants predominantly had type 1 diabetes and on average were 56 years old (range 46–64 years) and living with diabetes for 25 years (range 5–52 years), see Table 1.

Six themes about why older adults use the DOC were identified from the qualitative content analysis: 1) information to improve self-care, 2) emotional support, 3) belonging to a community, 4) validation of information, 5) cause for concern, and 6) interaction with HCPs.

3.1. Information to improve self-care

Participants actively sought knowledge about diabetes management and viewed the DOC as a tool that allowed them to improve diabetes self-management. Participants stated they gained more comprehensive knowledge of diabetes, learned about new developments in diabetes treatments and additional strategies for day-to-day management (i.e., management during exercise and travel, trouble-shooting devices). This information was commonly communicated through an individual describing a

Table 1
Demographics for Participants.

	N (%)
Gender	
Male	9(45)
Female	11(55)
Education Level	
Some College	4(20)
Associates Degree	2(10)
Bachelor's Degree	9(45)
Graduate or Professional Degree	5(25)
Race	
White	19(95)
Black or African American	1(5)
Diabetes Type	
Type 1	12(60)
Type 2	4(20)
Latent Autoimmune Diabetes of Adulthood (LADA)	4(20)
Technology Use	
Using an insulin pump	12(60)
Using a continuous glucose monitor	11(55)

Note. $N = 20$.

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