Journal of Diabetes Science and Technology
2019, Vol. 13(3) 466–492
© 2019 Diabetes Technology Society
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1932296819831042
journals.sagepub.com/home/dst
SAGE

State of the Science: A Scoping Review and Gap Analysis of Diabetes Online Communities

Michelle L. Litchman, PhD, FNP-BC, FAANP[1,2], Heather R. Walker, MS[3], Ashley H. Ng, PhD, APD[4], Sarah E. Wawrzynski, BSN, RN, CCRN[1], Sean M. Oser, MD, MPH[5], Deborah A. Greenwood, PhD, RN, CDE, BC-ADM, FAADE[6], Perry M. Gee, PhD, RN[1,7], Mellanye Lackey, MSI[8], and Tamara K. Oser, MD[5]

Abstract

Background: Individuals with diabetes are using online resources to engage in diabetes online communities to find diabetes-related support and information. The benefits and consequences of DOC (diabetes online community) use are unclear. This scoping review aims to map existing research focused on organic DOCs in which individuals affected by diabetes are interacting with peers.

Method: A scoping review was conducted to comprehensively report and synthesize relevant literature published prior to 2018. Attention was paid to variations in study design, DOC user and platform characteristics, and potential or actual benefits and consequences.

Results: Of the 14 486 titles identified, 47 articles met the inclusion criteria and were included in this scoping review. No overt definition of the DOC could be identified. Perceived or actual benefits associated with DOC use can be broadly categorized as clinical, behavioral, psychosocial and community outcomes. Perceived, potential, or actual consequences associated with DOC use were categorized as quality of information, risky behavior exploration, acute concerns, psychosocial, privacy, and inactivity.

Conclusions: The results of this review strongly suggest DOC use is highly beneficial with relatively few negative consequences. DOC use is an emerging area of research and research gaps exist. Future research should seek to identify benefits and consequences to DOC use in experimental trials.

Keywords
diabetes online community, type 1 diabetes, type 2 diabetes, scoping review, peer support

Diabetes is a complex chronic condition that requires ongoing self-management. People with diabetes (PWD) and their caregivers (ie, parent) spend less than 1% of their time in a year visiting with their diabetes health care provider (HCP).[1,2] As a result, PWD and their caregivers troubleshoot day-to-day activities on their own. It is estimated PWD spend 8000 hours per year self-managing their diabetes outside of the medical setting.[1] The Diabetes, Attitudes, Wishes and Needs Second Study (DAWN2) suggests PWD feel that their HCPs aren't always available to provide patient-centered care related to their diabetes.[3] This lack of support, intensity of diabetes management, and social stigma can be associated with burnout, diabetes distress,[4] higher hemoglobin A1C (A1C) and body mass index.[5] In

---

[1] College of Nursing, University of Utah, Salt Lake City, Utah, USA
[2] Utah Diabetes and Endocrinology Center, Salt Lake City, Utah, USA
[3] College of Applied Health Sciences, University of Illinois at Chicago, Chicago, IL, USA
[4] Department of Dietetics, Nutrition and Sport, La Trobe University, Bundoora, VIC, Australia
[5] Department of Family and Community Medicine, Penn State College of Medicine, Hershey, PA, USA
[6] Deborah Greenwood Consulting, Granite Bay, CA, USA
[7] Intermountain Healthcare, Nursing Research, Salt Lake City, UT, USA
[8] Spencer S. Eccles Health Sciences Library, University of Utah, Salt Lake City, Utah, USA

Corresponding Author:
Michelle L. Litchman, PhD, FNP-BC, FAANP, College of Nursing, University of Utah, 10 South 2000 East, Salt Lake City, UT 84112, USA.
Email: michelle.litchman@nurs.utah.edu

Table 1. Inclusion and Exclusion Criteria.

Criterion	Inclusion	Exclusion
Time period	Any date	N/A
Language	Articles written in English	Articles not written in English
Type of article	Original research, systematic reviews and meta-analyses published in a peer reviewed journal	Articles that are not original research or published in a peer reviewed journal or are conference abstracts
Study focus	Articles focused on teens/adults with T1D/T2D or caregivers of children with diabetes interacting with peers in the organic DOC	Articles that mention online health seeking behavior without mention of interaction with peers, examined of a researcher-developed DOC, examined patient-provider interaction within the DOC, used the DOC as a source of recruitment but did not explore peer interactions, or focus was mobile health apps or telehealth
Population and sample	Teens/adults with T1D or T2D or caregivers of children with diabetes	Individuals not affected by diabetes

order to fill these gaps, PWD are seeking peer support in online and in-person settings.

Individuals are turning to the Internet to find support and information about their diabetes. In the United States, 23-39% of emerging adults and adults with chronic conditions are seeking peers online.[6,7] The American Diabetes Association and the American Association of Diabetes Educators have endorsed the importance of peer support,[8-10] such as the Diabetes Online Community (DOC). Further, the American Association of Diabetes Educators has embarked on an initiative to work closely with DOC leadership.[11] Although no studies have been performed to date, the rise in social media use coupled with an increasing number of presentations and research reports focused on the DOC suggests its ongoing growth. Despite this likely increase, we do not fully understand the benefits and negative consequences associated with DOC use. Further, there are no guidelines to assist HCPs in making recommendations to their patients about DOC use.

Understanding that a wide range of methods and outcome variables have been used to explore the DOC, the purpose of this scoping review is to map the current research focused on organic DOCs to characterize the reported positive and negative aspects of DOC use. For the purposes of this study, an organic DOC is defined as a grassroots group of individuals living with or caring for someone with diabetes who gather in online spaces to interact with peers. Although the DOC includes HCPs and industry stakeholders, we only explored research focused on peer-to-peer engagement. Organic DOCs were selected given their relative accessibility and their emerging body of literature. In this paper we will draw conclusions from existing literature regarding the state of the science and identify gaps in the literature.[12,13]

Methods

We used a rigorous and transparent five step approach[13] to guide this scoping review. The steps included (1) identifying the research questions, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, and (5) collating, summarizing, and reporting the data. Although not typically reported in scoping reviews, the research team assessed the quality of data in order to fully describe the included studies in this emerging field of research. Our approach, as detailed below, should allow for replication of the search strategy, increasing the reliability of our findings.

Research Questions

The focus of this scoping review was to characterize the DOC and the positive or negative aspects of organic DOC use. To ensure the appropriate literature was captured, we posed the following research questions.

1. How is the DOC defined?
2. How are the DOC platforms and its users characterized?
3. What actual or perceived benefits are associated with organic DOC use?
4. What actual or perceived negative consequences are associated with organic DOC use?
5. What gaps exist in the current DOC literature?

Identifying Relevant Studies

A combination of search terms about diabetes and social media were used and a sensitive search was performed to assure broad retrieval of relevant literature on 19 March 2018 and again on 25 October 2018. No date limitations were set in order to include all known literature in this review. Inclusion and exclusion criteria are listed in Table 1. Terms about communities were intentionally omitted as their use was not consistent among a sample set of desired citations. A medical librarian developed the search strategy using Ovid/MEDLINE (ovid.com) and then translated it for: EMBASE (embase.com), CINAHL (EBSCOhost), PsycINFO (EBSCOhost), Web of Science, and Communication and Mass Media (EBSCOhost). Key search terms and the complete search strategy developed for Ovid/MEDLINE is listed in Table 2.

Table 2. Ovid/MEDLINE Search Strategy.

Search strategy
(exp diabetes mellitus/ or ((diabetes or diabetic*) and (Juvenile or adult onset or Type 1 or type one or type 2 or type two)).ab,ti. or (diabetes or diabetic*).ab,ti.) AND ((exp internet/) OR (exp social media/) OR ((internet OR social media OR social network* OR Pinterest OR YouTube OR Facebook OR Skype OR Instagram OR Tumblr OR myspace OR Friendster OR ello OR google circles OR google buzz OR orkut OR dailymotion OR twitter OR blog* OR world wide web OR online OR mHealth OR website*).ab,ti.))

Study Selection

The search strategy yielded 14 486 studies. Covidence systematic review software (http://www.covidence.org) was used following the removal of duplicate citations.[14] An additional 21 papers not retrieved in database searches were identified. The authors independently screened titles and abstracts for relevance. Full-text articles were double-blind reviewed by two authors for inclusion. Two additional authors resolved disagreements. Thus, 47 articles were included in this scoping review. Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[15] were used to describe the article selection process (Figure 1).

Data Charting

Summaries of each article were documented, noting the author, year, study aims, methods, sample, location, themes, outcome measures, results, ethics approval, funding source, and data quality. Covidence was used to tag studies. Tags included (1) sample (child with diabetes, <12 years; adolescent, 13-18 years; parent of child with diabetes; person with diabetes, T1D; person with diabetes, T2D); (2) setting (Facebook, Twitter, Instagram, online forum, other); (3) location (based in United States, not based in United States); (4) method (qualitative; quantitative; review); (5) outcome (psychosocial, clinical, behavioral).

Assessing Data Quality

Joanna Briggs Institute critical appraisal checklists[16] were selected to assess the methodological quality of the selected articles given the breadth of research designs included in this scoping review. Two authors assessed and reached consensus for all 47 selected studies. Checklists were unavailable for social network analysis and text mining studies. For these studies, authors reached consensus through discussion. No studies were omitted due to the quality of data being too poor. Quality assessment checklists are described in detail in Appendix A.

Results

Study Selection

This scoping review initially identified 14 483 articles. After removing duplicates and ineligible reports, 47 articles representing 43 studies were examined. Study methodology varied and was categorized as cross-sectional, prospective qualitative, retrospective qualitative, social network analysis, and text mining (Tables 3-6).

1. Research Question 1: How is the DOC defined?

There were no overt definitions of the DOC. Litchman et al[34] described the DOC as having components of peer health, defined as “the interaction, education, and support offered by peers with the same condition to promote health-enhancing change.”

2. Research Question 2: How are the DOC platforms and its users characterized?

DOC Platforms, Users, and Measures

A variety of DOC platforms (Twitter, Facebook, Google+, YouTube, and blogs) were used to examine DOC users, with the most common being online forums. One study[35] explicitly looked at DOC users engaging in more than one platform and two studies recruited from multiple DOC platforms, but did not explicitly identify users who engaged with multiple platforms.[21,34] Each platform investigated seem to have its own dedicated userbase with little overlap between DOC users. DOC users spanned at least 92 countries. Most studies focused on T1D.[17,18,24,25,27,37,38,50,52,53,57,58] Twenty articles contained demographic information about DOC users.[17-19,21,23-25,27-34,37-39,41,48,53] Age of DOC users range from 12-82 years.[17,18,21,23,25,27-34,37] Overall, there were more female than male DOC users examined.[17,21,23,24,27,30-32,34,35,38,39,48,53] The majority of DOC users were white[17-19,21,25,27-29,34] college graduates[17,21,23,25,27,34] with few healthcare provider users. Lurkers, individuals who read but do not generate posts were described.[31,32] There were a variety of ways in with DOC use was measured, which included activity, intensity, engagement, time spent, and number of posts (Table 7).

3. Research Question 3: What actual or perceived benefits are associated with organic DOC use?

Actual or perceived benefits associated with DOC use were categorized on the individual level, which focused on clinical, behavioral, and psychosocial outcomes; and on the collective level, which focused on community building (Table 8).

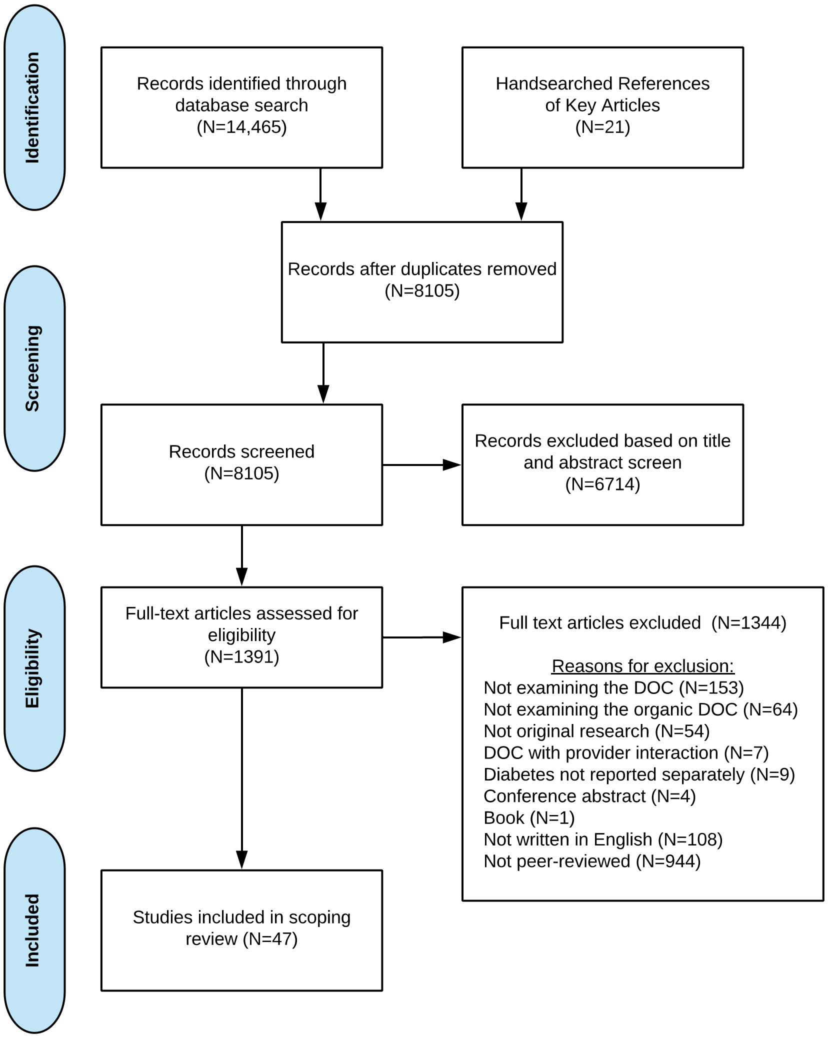

Figure 1. PRISMA diagram.

Clinical

In the studies reviewed, DOC use supplemented clinical care, but did not replace it.[21,22,34,36] Of DOC users, 87% saw their HCP at least biannually.[21] Clinical measures were used to gauge outcomes associated with DOC use, including self-reported A1C and survey items exploring HCP support of DOC use.

A1C. Self-reported A1C had neutral or beneficial associations with DOC use.[17,18,21,25,41,56] A1C was neutral among children whose parents used the DOC[17,18] and adolescents.[25] Conversely, in adult DOC users with T1D and T2D, high levels of DOC engagement predicted A1C. For every point increase on a 5-point DOC engagement scale, there was a 33.8% reduced odds of having an A1C ≥ 7.0%, although causation could not be determined.[21] In one study, A1C was within target range for DOC users engaging in patient-driven innovation, such as the open-source artificial pancreas.[41] Although no analysis correlated A1C to frequency of posting, in a social network analysis of 107 927 posts, the "majority" (no sample size defined) disclosed an A1C ranging from 6-9%.[56] No studies examined biophysical measures of A1C.

HCP Support of DOC Use. Some (31-67%) DOC users had not discussed their DOC use with their HCP.[19,21] Those with T1D were more likely to disclose; however, those with T2D felt more supported when they chose to disclose.[19] DOC use was higher among PWD who told their HCP of their DOC use and felt supported to continue.[21] DOC users wanted HCPs to read DOC postings to enhance their understanding of living with diabetes and the value the DOC has for its users,[28] but did not suggest that HCPs interact with DOC users online. Few (2%) DOC users were not supported by their HCP to use the DOC,[21] perhaps because the HCP didn't understand the benefits.[29]

Table 3. Cross-Sectional Studies.

Author/year	Aims	DOC platform	Sample	Location	Outcome measures	Results
Balkhi et al[17]	To assess demographic usage habits of individuals using diabetes forums and to test the stated view of physicians that online forums are problematic	Online forum	N = 102 caregivers of CWD	USA	Pediatric Inventory for Parent; Hypoglycemia fear scale (parent version); Diabetes Knowledge Test; Trustworthiness; Forum Membership; open-ended items on reasons and largest benefits for visiting T1D websites	Largest reported benefit of being involved with the DOC included social support (38.2%), knowledge (31.4%), social support and knowledge together (21.6%). DOC trustworthiness is higher ($M = 2.49$) compared to general Internet use ($M = 2.97$, $SD = 0.94$); $t(100) = -5.621$, $P < .001$. Forum use predicted parented stress frequency ($\beta = 0.28$, $P < .01$) with a small effect size but not associated with parenting stress difficulty. Forum use predicted hypoglycemia fear behaviors ($\beta = 0.23$, $P < .05$) with small effect size controlling for Internet use time, child age, years post diagnosis, parent age, and child gender.
Balkhi et al[18]	Prevalence of online health seeking behavior in T1D caregivers	Online forum	N = 209 caregivers (49% recruitment rate); 73% mothers	US, Southeast region	Self-Reported A1C; Internet Access; Online Health Information Seeking Behavior	92.6% have internet access; 63.6% use the internet for diabetes information; 45.5% use social media (120.95 minutes/week, SD = 159.05, range 5-900 minutes); message boards used by 22% (74.6 minutes/week, SD = 72.21, 5-480 minutes). Child age negatively correlated with message board time ($r = -.20$, $P < .01$). Parental management style (high coding = more management) negatively correlated with social media time ($r = -.16$, $P < .05$).
Browne et al[19]	Understand the perceptions, preferences, and experiences of peer support from the perspective of adults with T1D and T2D	—	N = 2342 (T1D n = 1078, 46%; T2D n = 1263)	Australia	Online survey using Likert-type scale	Current user of OzDOC 17/224 (7.6%), Facebook 47/224 (21%), online forum 54/224 (24.1%). People who wished to participate in peer support endorsed online (Facebook, OzDOC or forums) 38% of the time (N = 658).

(continued)

Table 3. (continued)

Author/year	Aims	DOC platform	Sample	Location	Outcome measures	Results
Cole et al[20]	Improve understanding of the quality and quality characteristics of information found in online discussion forum websites so that their likely value as a peer-to-peer health information-sharing platform could be assessed	Reddit, Mumsnet, Patient	N = 25 (health discussions across 3 websites) N = 78 assessments by 17 individuals (8 medical doctors, 9 were not) Specific to diabetes, there were 8 questions and N = 113 assessments made	UK	Likert-type scale questionnaire: 1. The medical/scientific accuracy of information found 2. The medical/scientific completeness of the information 3. How sensible they considered the answers provided to be 4. Whether they thought someone reading the website would act appropriately based on information provided 5. How useful they felt the answers given would be to original poster	There was only 1 low rating recorded. One of the four assessors felt the information was "very medically/scientifically inaccurate" but did not feel the information would lead the poster to make an ill-advised decision or act in a way that would put their health at risk. Forums that contained inaccurate or controversial information also contained counterbalancing comments that diluted potentially harmful consequences of harmful information. Reddit contained highest quality information out of all three forums but also more likely to contain lowest quality information.
Litchman et al[21]	To understand and describe the DOC users, how they are using it and associations between DOC use and health indicators	Mixed	N = 183 adults with diabetes (n = 129 T1D; n = 33 T2D; n = 21 LADA)	US 151 (82.5%) Not US 31 (16.9%)	Demographics; Health history; eHealth use questionnaire (reasons to join a social network, intensity of DOC Engagement) Health-related Quality of Life; Diabetes self-care	58 out of 183 (32%) participants reported using the DOC for less than a year. 38% reported using the DOC between 1-3 years and 30% reported using the DOC for over 3 years. Of those who told their health care provider about their DOC use, 60% (36/60) were supportive, 2% were not supported and 11% were unsure if their HCP supported DOC use. DOC use was higher if participants had told their HCP about their DOC use and were supported. Diabetes self-care ($P < .001$) and quality of life ($P < .001$) scores were higher in DOC users compared to norms for diabetes. DOC engagement strongly predicts A1C reducing the odds of having an A1C $\geq 7\%$ by 33.8% for every 1 point increase on a 0-5 scale.

(continued)

Table 3. (continued)

Author/year	Aims	DOC platform	Sample	Location	Outcome measures	Results
Nelakurthi et al[22]	To evaluate the use of social media of individuals with diabetes mellitus	—	N = 45	UK and US	Web-based and in-clinic surveys: demographic information; educational level; marital status; diabetes-specific information (eg, diabetes diagnosis, most recent hemoglobin A1c [HbA1c] value); nature and frequency of diabetes-specific social networking site usage; dietary habits and diabetes self-care activities and reasons for using the site	Positive correlations between offering advice on social media and eating and exercise habits; website use was positively associated with integrating advice read; 52/85 (63%) reported that websites helped them with communication with their health care provider.
Oh and Lee[23]	To test the mechanism through which Korean diabetes patients' exchange computer-media social support in DOC influences on their sense of empowerment and intention to actively communicate with the doctor	Online forum	N = 464 adults with diabetes	Korea	Online community activity; perceived CMSS; empowerment; intention to communicate with HCP	DOC activity positively associated with patient's perceived CMSS ($\beta = 0.27$, $P < .01$). Perceived CMSS is a strong predictor of sense of empowerment ($\beta = 0.60$, $P < .1$). Sense of empowerment is associated with intention to communicate with their HCP ($\beta = 0.62$, $P < .01$). Perceived CMSS and intention to actively communicate with HCP was mediated by a sense of empowerment (z-value of 8.19, $P < .01$). Of the types of CMSS, informational support was the strongest predictor of sense of empowerment.

(continued)

Table 3. (continued)

Author/year	Aims	DOC platform	Sample	Location	Outcome measures	Results
Sparud-Lundin et al[24]	Explore internet use, needs, and expectations regarding web-based information and communication in childbearing women with T1D	—	N = 105, women with T1D and recent childbearing experience	Sweden	Questionnaire covering sociodemographic factors; use of the internet for information seeking and communication in general, diabetes-related issues and specific questions on needs in relation to childbearing	The most common reason for seeking diabetes-related information on the internet was in relation to childbearing (48 of 73 women, 66%) and when planning pregnancy (43 women, 59%). Searching for specific information at the onset of diabetes was reported by 24 women (33%). Twelve women (12%) searched for information every day, 30 women (29%) one or more times a week, and 39 women (38%) one or more times in the past month. This study showed that a high proportion of women with type 1 diabetes seek diabetes-related information on the internet, especially before, during, and after pregnancy. The great majority participated in social websites (80.6%), and 50% of these reported active participation. 46.5% used blogs and/or forums. Almost half of the participants stated needs and/or expectations of support.
Vaala et al[25]	Examine adolescent and parent use of 5 commonly available technologies for diabetes	—	N = 174 adolescent-parent pairs, 134 recruited from pediatric diabetes clinic, 40 recruited from the Children With Diabetes community website	—	Diabetes self-management (Self-Care Inventory–Revised, SCI-R); access to technology; adolescent technology use; parent technology use; reasons for use/nonuse of technology; A1c (for clinic-recruited participants, not for online-recruited participants)	Specifically for diabetes-related purposes, 27.6% and 24.7% of adolescents reported used social networking and websites, respectively. Among adolescent users of social networking, 75.0% reported doing so in order to help others; among adolescent users of websites, 74.3% reported doing so in order to help solve diabetes-related problem, while 72.1% agreed that using websites helped them feel better about living with diabetes.

(continued)

Table 3. (continued)

Author/year	Aims	DOC platform	Sample	Location	Outcome measures	Results
van Berkel et al[26]	Investigate whether discussions about medicine use take place on online message boards contribute to patient empowerment and could subsequently result in more effective use of medicines, discuss the extent to which patient empowerment processes occur in discussions on online message boards	Online forums	N = 35 message boards	Country not specified (language—Dutch)	Empowerment processes: Providing information Requesting information Sharing personal experiences Exchanging empathy or support Gratitude Comparison with other members Off-topic, everyday talk	Posts Breakdown n = 1130 (46%) Providing information n = 472 (19%) Requesting information n = 1152 (47%) Sharing personal experiences n = 324 (13%) Exchanging empathy or support n = 111 (4.5%) Gratitude n = 74 (3.0%) Comparison with other members Information requested n = 283 (60%) Supplementary information n = 78 (17%) Other n = 27 (5.5%) Blood sugar levels n = 24 (5%) Dealing with medicines/ disorder n = 22 (4.5%) Diagnosis n = 17 (3.5%) Use of medicines n = 17 (3.5%) Dosage n = 4 (1%) Effects of medicines Quality of information n = 853 (75.5%) Harmless information n = 190 (17%) Correct information n = 80 (7%) Disputable information n = 8 (0.5%) Incorrect information
White et al[27]	Describe individual motivations for participation in an online social media community and to assess their level of trust in medical information provided by medical professionals and community members	CGM in the Cloud Community	N = 1268 Caregiver = 1026 (80.9%) PWD 242 (9.1%) Relative = 110 (8.7%) Friend = 61 (4.8%) Works in diabetes = 54 (4.3%) Spouse/SO = 53 (4.2%) Other = 2 (0.2%)	US	Minutes/day spent in CGM in the Cloud FB group	Themes identified: (1) awareness (spreading awareness to providers, spreading awareness to patients), (2) technical assistance (design, setup, troubleshooting), (3) general support (emotional, informational), and (4) donation (monetary, hardware)

Table 4. Prospective Qualitative Studies (Interviews/Focus Groups).

Author/year	Aims	DOC platform	Sample	Location	Themes/findings
Prospective					
Brady et al[28]	To understand how privacy is experienced and enacted online by adults with chronic illness	Online forum	N = 21 adults with diabetes (n = 12 T1D; n = 9 T2D)	UK	• Presentation of self-online • The value of sharing information online • Curating the information shared online • Online audiences
Brady et al[29]	To understand how online communities may influence empowerment to engage in their own health care	Online forum	N = 21 adults with diabetes (n = 12 T1D; n = 9 T2D)	UK	• Accessing support and shared experiences online • The internet as a tool of empowerment • The value of reciprocal support online • Accountability for self-care
Fergie et al[30]	Explore perceptions and experiences of engaging with health information online in a sample of young adults familiar with social media environments and variously engaged in consuming user-generated content.	YouTube, Facebook, and Twitter pages, featuring user-generated video-blogs	N = 20 adults with diabetes	UK	• Motives and intentions for accessing health-related content (fact-finding, accessing others' accounts, combining fact-finding and accessing others' accounts, timing and context, critical junctions, ongoing concerns, and everyday engagement) • Navigating health-related content online (locating relevant content, assessing online resources—determining credibility and reliability)
Fergie et al[31]	Explore how engagement with user-generated content can support people with long-term health conditions, and what limits users' adoption of these technologies in the everyday experience of their health condition	Facebook, YouTube, and Twitter pages, featuring different types of online content (images, text extracts and videos)	N = 20 adults with diabetes	UK	• Engagement with health-related user-generated content in relation to offline support (nonengagers, prosumers, tacit consumers, temporality and movement between types) • User's considerations of identity and audience on social media sites (producing health-related content, expectations of appropriate online practices in social media spaces)
Gilbert et al[32]	Identify what stakeholder groups most value the Reality Check online community	Online forum	N = 6 focus groups with 42 T1D	39 (93%) Australia, 2 (5%) UK, 1 (3%) New Zealand	• Assistance in applying diabetes management in daily life (sharing real-life experiences of living with diabetes, help in identifying key resources) • Ongoing emotional support (empathetic listening, providing encouragement, support to stay motivated, help coping with social and emotional barriers) • Ongoing availability of support • Proactive contact (ongoing availability of support, proactive contact) • Assistance in applying diabetes management in daily life (problem solving, learning, improve management of diabetes, feel supported, self-reflection, connection and interaction with peers, sense of community, assisting others)

(continued)

Table 4. (continued)

Author/year	Aims	DOC platform	Sample	Location	Themes/findings
Hastings et al[33]	Explore how group memberships (and the associated identities) both contribute to and hinder the recovery of diabulimia	Online forum	N = 13 adults with diabetes; N = 5 online focus groups	UK and USA	• Not like everyone else (self-distinction from other patients, dismissal of HCPs) • Shared identity online promotes recovery (acceptance and validation of diabulimia community, facilitation of symptom management, shared learning) • Threats to recovery (self-management—when diabulemic is not a helpful identity, group self-regulation) • Recovery outside of the diabulimia group (accessing services, talking to non–group members, owning the group identity)
Litchman et al[34]	Describe why older adults participate in the DOC and how they interacted with their HCPs	DOC	N = 20 baby boomers with diabetes (n = 12 T1D; n = 4 T2D; n = 4 LADA)	USA	• Information to improve self-care • Emotional support • Belonging to a community • Validation of information • Cause for concern • Interaction with HCPs
Newman et al[35]	Understand why and how people share health information online (participants have diabetes and want to lose weight)	Facebook and online health communities (FatSecret, Personal Blog, Diabetes Daily, SparkPeople, TuDiabetes)	N = 14 T2D	Not reported	• Emotional support • Accountability • Motivation • Advice • Impression management • Building and shaping the network
O'Kane et al[36]	Examine the self-management practices of people who are dealing with unique triggers, symptoms, and treatments	Online forum	N = 32 adults with diabetes (n = 9 interviews; n = 1 focus group with 20 participants; n = 3 interviews with bloggers)	UK and USA	• The struggle to identify if personal data is normal • Medical information sources are not adequate for validating normality • New opportunities in validating normality through turning to peers
Rasmussen et al[37]	Explore and describe the strategies young women with T1D used to manage transitions in their lives with a specific focus on using the internet to interact with other PWD	Email and online forum	N = 20 women with T1D	Australia	• Safeguarding anonymity using websites and emails • Using websites and emails to achieve stability in new environments
Sparud-Lundin et al[38]	Explore the meaning of interactions with supports of self-management from parents and other significant others for young adults with T1D	Online forum	N = 13 young adults with diabetes; N = 13 parents of CWD	Sweden	• Reconstructing meanings of supportive relationships with parents: becoming guiding agents, relinquishing responsibility, conflict-creating concern • Reconstructing meanings of supportive relationships with other significant others: siblings standing by, concerned but unqualified partners, managing friends' involvement, contradictory interchange of diabetes experiences • Reconsidering self: becoming aware of identity threats, growing acceptance

(continued)

Table 4. (continued)

Author/year	Aims	DOC platform	Sample	Location	Themes/findings
Retrospective					
AlQarni et al[39]	Examine the type of information sharing and potential health consequences on the patients and their relatives in the Arabic speaking world with a focus on diabetes	Facebook	N = 1551 posts from 7 groups	Egypt, 29.5% Lebanon, 20.1% Sudan, 16.1% Saudi Arabia, 7.7% Algeria, 6.3% Not identifiable, 5.2% Syria, 4.8% Iraq, 3.5% Morocco, 2.2% Jordan, 1.8% Palestine, 0.71% United Arab Emirates, 0.58% Libya, 0.45% Tunisia, 0.32% Oman, 0.25% Bahrain, 0.19% Kuwait, 0.13% Qatar, 0.13% Mauritania, 0.13%	Foci of posts included: • Sharing personal experiences, 27.3% • Support for patients and caregivers, 14.2% • Raising awareness on diabetes, 13.5% • Providing spiritual support, 10.4% • Sharing latest research, 9.5% • Seeking or clarifying personal status, 9.0% • Educational, 7.1% • Product and service promotion, 5.5% • Sharing recipes, 3.5%
Arduser[40]	Examine the texts posted by members of TuDiabetes in order to discern the values held by this community	Online forum	N = 3158 posts; Email interviews with site organizer and 3 active users	Not reported	• Welcome to the club • We don't need no stinking doctor • Bad patient • The common rhetorical thread
Beguerisse-Díaz et al[41]	To explore themes that arise in tweets that contain #diabetes hashtag, to understand who the most influential users are in the diabetes Twitter community and to explore the association between the type of users and their corresponding themes	Twitter	N = 2 698 114 tweets; 1 219 282 retweets; 41 582 friend-follower relationships	Not reported	• Health information: public health messages; diabetes information links; population health fears; publicity about outreach and awareness; advice about diabetes management and diagnosis; lifestyle tips, news, and links; life stories and experiences; dangers of sugar, sweeteners, and soda • News: links to "breakthrough" studies or technologies; celebrity news; general news about pets or people with diabetes; news relating to industry and the economy • Social interaction: jokes about food likely to give users diabetes; chatter and social interchanges that mention diabetes; everyday experiences of diabetes; stigmatizing comments; banter, innuendo, and humor relating to sweetness and diabetes • Commercial: advertisements for jobs in industry and health care; marketing (specific services, products, apps, events, treatments, diets); updates and FDA approvals

(continued)

Table 4. (continued)

Author/year	Aims	DOC platform	Sample	Location	Themes/findings
Bond et al[42]	Explore information shard on discussion boards for people living with diabetes	Online forum	N = 148 threads (range 1.05-1.83 posts per user)	Not reported	• Information sharing from experience: nutritional and dietary; diagnosis; self-management techniques; health care interactions including dealing with HCPs and questioning HCPs; medication; living with diabetes • Signposting other sources of information: referral to another source; reference to research, comments on quality of information (including self-moderation of information, acknowledging lack of qualification to offer medical advice); your mileage may vary (what works for one may not work for another)
Greene et al[43]	Qualitatively evaluate the content of communication in Facebook communities dedicated to diabetes	Facebook	N = 15 largest Facebook groups focused on diabetes, including 233 wall comments and 457 discussion topic comments	Not reported	• Information sharing • Patient-centered management; interpersonal support and community building • Facebook as a marketing space
Hoffman-Goetz et al[44]	Determine whether peer recommendations made in response to user queries about non-insulin-dependent T2D in an online forum for retired persons were in agreement with diabetes clinical practice guidelines	Online forum	N = 17 responses to user questions, including 35 individual recommendations	Canada	• Signs and symptoms • Glycemic control • Neuropathy; retinopathy • Diet and physical activity recommendations • Prednisone and glucose control
Huh et al[45]	Understand how patient-initiated vlogs shape the relationships among vloggers and viewers	Vlogs	N = 24 vlogs (2 posts each from 12 vloggers), 42 associated comments from 36 commenters	Not reported	• Helping others, including educating, encouraging, and inspiring, 71% • Journaling, including self-reflection and updates, 21% • Entertaining, 8%
Kelly et al[46]	Critically evaluate the quality of nonprofessional advice available on the internet for people with diabetes	Online forum	N = 61 messages generated 242 responses from 146 respondents	Not reported	• Personal opinion/anecdote, 56.6% • Accepted wisdom, 24.8% • Misleading/irrelevant, 10.7% • Evidence based, 5.4% • Possibly dangerous, 2.1% • False, 0.4%
Koteyko and Hunt[47]	Examine the role of Facebook in the lives of users with T1D and T2D and the multimodal discursive practices they employ in their outgoing representation with a long-term condition	Facebook	N = 20 purposive sample of Facebook users' profiles, including 685 timeline contributions, 201 page and group contributions, and 508 likes	Not reported	• Constructing personal expertise in relation to diabetes management • Building and maintaining diabetes-related networks • Reporting on mundane aspects of self-management • Using play to negotiate social and professional expectations of diabetes self-management
Lewis et al[48]	Investigate the reasons that older adults join a DOC to better understand the specific resources that are being sought	TuDiabetes	1969 statements from people over 65 with Type 2 who signed up for TuDiabetes	—	• General information • Self-management, share/support/companionship, informational support • Social support

(continued)

Table 4. (continued)

Author/year	Aims	DOC platform	Sample	Location	Themes/findings
Libreri and Graffigna (2012)[49]	Understand the role of Web 2.0 contexts into shape online exchanges about diabetes in Italy	Online forum, Facebook, blogs, social network pages, groups and Q&A sites	N = 156 references	Global but focused on Italy	• Popularizing scientific knowledge • Informing about diabetes and related activities • Educating on diabetes and its management • Sharing knowledge and support
Litchman et al[50]	Examine stakeholder perceptions of successful aging with diabetes on the Twitter diabetes chat #DSMA	Twitter	N = 494 Tweets from 59 individuals (36 people with diabetes, 15 caregivers/advocates, 8 other)	USA, 53% Unknown, 32% Canada, 5.1% Italy, 3.4% Sudan, 1.7% Philippines, 1.7% Peru, 1.7% Australia, 1.7%	• Personal decline now and in the future • Limited access to treatment • Inability to provide self-care • Health care provider capacity to support aging with diabetes • Lifelong online peer health support to facilitate diabetes management
Litchman et al[51]	Examine Twitter data to understand how patients, caregivers and care partners perceive OpenAPS, the personal and emotional ramifications of using OpenAPS, and the influence of OpenAPS on daily life	Twitter	N = 3347 Tweets from 328 patients, caregivers and care partners	92 countries	• OpenAPS changes lives • OpenAPS use suggests self-reported A1C and glucose variability improvement • OpenAPS improves sense of diabetes burden and quality of life • OpenAPS is perceived as safe • Patient/caregiver-provider interaction related to OpenAPS • Technology adaptation for user needs
Mogi et al[52]	Characterize Google+ communities related to diabetes and identify the factors associated with the activity level of these communities	Online forum	N = 145 Google+ communities with 378 posts	Not reported	• Provide support and share experiences, 35.2%; others, 21.4%; diet-related topics, 20.7%; exercise-related topics, 16.6%; product and service promotion, 15.2%; awareness creation, 11.7% • Providing information, 72.8%; advertisement, 31.5%; expressing emotion, 14%; asking for information, 6.3% • Among communities, 44.1% were "active" and 55.9% "less active"; communities about diet-related topics were more likely to be active (OR 3.68, 95% CI 1.12-12.14)
Oser et al[53]	Analyze blogs of caregivers to children with T1D to better understand the challenges and successes they face in raising a child with T1D and to assess the blogs for presence of safe and inaccurate medication information or advice	Blogs	N = 140 blog posts, 663 comments from 3 blog sites	Not reported	• Impact of the child's diagnosis • The burden of intense self-management experienced in caring for a child with T1D • Caregivers' use of technology to ease their fear of hypoglycemia and impacts that device alarms associated with this technology have on caregiver burden • Caregivers' perceptions of frequently missed or delayed diagnosis of T1D and the frustration this causes • The resilience that caregivers develop despite the burdens they experience; especially through peer support on blogs and advocacy efforts • No misinformation in any blog posts, 0%; incidents of possible misinformation in 2 comments, 0.3%

(continued)

Table 4. (continued)

Author/year	Aims	DOC platform	Sample	Location	Themes/findings
Ravert et al[54]	Examine the nature of messages posted at online diabetes forums among adolescents with diabetes, identify differences found among subgroups, examine how messages posted for health professionals differ from peers in public discussion forums	Online forum	N = 340 messages: 185 (55%) from discussion forums, 155 (46%) from Q&A forums)	Not reported	• Request for information (related to life tasks, social support, medical care, factual information, management, and intrapsychic posts related to state of mind and attitude, such as coping, eating disorders) • Reply to query • Combination of request and reply • Unsolicited offer of help • Social support posts comprised 50% of discussion forum messages but only 1.1% of Q&A posts. No relationship between duration illness or age and type of community used. No gender differences in types of posts.
Zhang et al[55]	Identify characteristics of the Facebook diabetes group "Diabetes," including who the participants are and what activities they perform in the group, and how users interact with one another in the group	Facebook	N = 1352 messages contributed by 479 unique participants	USA UK Australia Ireland Canada Brazil Dubai Spain Philippines South Africa	• Providing information, 62.6% • Providing emotional support, 17.2% • Expressing emotions, 13.7% • Eliciting information, 12.1% • Community building, 5.4% • Seeking emotional support, 0.7

Table 5. Social Network Analysis Studies.

Author/year	Aims	DOC platform	Sample size	Results
Chomutare et al[56]	Assess the extent of inferring meaningful community structures from implicit networks of peer interaction	Online forum	N = 5 online forums that contained a total of 142 103 users The sites reported an average of 28.80% of users posting in the forum	78% of users with diabetes duration <2 years Central nodes with diabetes duration ≥ 2 years Users with 2-10 years diabetes duration most active in supporting newly diagnosed users Homophily negative (node degree not necessary for group cohesion) Users struggling the most were parents of CWD
Chomutare et al[57]	Understand the temporal patterns of the communities, observe attributes that influence temporal community cohesion and identify patterns that characterize the networks	Online forum	N = 2 diabetes online forums (107 927 posts) N = 2 non-health online forums	80% of users with diabetes duration <2 years Information dissemination from few central nodes to large number of nodes Majority disclosed A1C, range 6-9%
Chomutare et al[57]	Understand the temporal patterns of the subcommunities and observe attributes that influence temporal community cohesion	Online forum	N = 2 online forums (107 927 posts)	80% of users with diabetes duration <2 years Once these newly diagnosed users (under 2 years) become comfortable with their diagnosis they tend to move on Long-term users tend to be moderators and administrators
Dias et al (2012)[58]	Identify the key actors and their role in the community	Online forum	N = 1 online forum (>30 000 registered users, >200 000 posts)	People with more experience (>2 years since diagnosis) held central positions in the community Newly diagnosed (<2 years) were very active in the community 1) learned from the more experienced; 2) disseminated information to others

Table 6. Text Mining Studies.

Author/year	Aims	DOC platform	Sample	Findings
Chen[59]	Characterize and compare online discussion forums for three conditions: breast cancer, T1D, and fibromyalgia	Online forum	N = 2806 posts by 516 individuals on 487 discussion threads; mean 5.76 posts per thread	Topic clusters included: Personal experiences (dealing with others, recently diagnosed, dealing with emotional lows) Not related to a specific medical situation (miscellaneous, website references, resources for diabetes, new member introductions, study solicitations, introductions, and study invitations and announcements) Support (reaching out to others, seeking friends and insurance, asking others' opinions) Diabetes management (low blood sugar, eating, blood sugar control, diet/weight control, complications/pregnancy, doctors) Insulin management (types of insulin, insulin pumps)
Liu et al [60]	Examine diabetes-related participation on Twitter by describing the frequency and timing of diabetes-related tweets, the geography of tweets, and the types of participation over a 2-year sample of 10% of all tweets	Twitter	N = 1 368 575 tweets	Globally, people with diabetes are increasingly using social media as a place to discuss diabetes related communications. A small percentage of users were health care providers.
Lu et al (2017) [61]	Identify different health care stakeholders, determine hot topics of concern, and measure sentiment expression by different stakeholders	Online forum	N = 35 193 posts by 11 571 individuals; 3.04 posts per individual	Stakeholder groups (user clusters) included: Patients, 49.6%; Caregivers, 41.8%; Specialists, 8.6% Topic clusters, % of patient posts mapped to cluster: Drug, 31.9%; Complications, 22.7%; Symptoms, 19.9%; Examination, 16.5%; Procedure, 9.0% Informative messages more prevalent than emotional messages; 57.1% vs 33.6% for patients posts, 78.6% vs 18.6% for caregivers Most posts implied no sentiment, but where sentiment existed, it changed over time. For patients, negative sentiment was greater than positive at first, but this gap narrowed over 6 months of forum use, reversed at the 6 month mark, and positive remained narrowly greater than negative for the next 6 months. For caregivers, negative sentiment remained greater throughout all 12 months, but the gap narrowed progressively until stabilizing around month 9.
Troncone et al[62]	Assess messages posted by mothers of children with T1D in the Italian Facebook Group "Mamme e diabete" using computerized text analysis	Facebook	N = 40 355 posts	Topic clusters included: Insulin dosing/glucose correction, 20.2% Emotional correlates of diabetes and its management, 18.5% Group participation, encouragement, and emotional support, 16.8% Bureaucracy, 15.8% Needles for glucose checking, insulin injection, insulin pump maintenance, 15.3% Food, 13.4%

Table 7. Measures of DOC Use.

Measurement tool	Description	Author
Activity	Summary score of 4 questions related to length of DOC membership, time spent using the DOC, and number of contacts within the DOC; no coefficient reported	Oh and Lee[23]
Intensity	Modified 8-item Facebook intensity scale examining time spent and number of friends within the community; α = .85	Litchman et al[21]
Engagement	Summary score of a 5-item, researcher-developed, tool examining sharing, providing, or requesting information or emotional support; α = 73	Litchman et al[21]
Minutes	Number of minutes per day	Balkhi et al[17] Balkhi et al[18] White et al[27]
Days	Number of days per week or month	Gilbert et al[32] Sparud-Lundin et al[24]
Posts	Number of posts	Chomutare et al[56] Chomutare et al[55]

Psychosocial

There were a myriad of psychosocial benefits noted. Health-related quality of life was higher in DOC users when compared to a general population of PWD. DOC users engaged in patient-driven innovation, experienced reduced diabetes burden and enhanced quality of life. While only two studies explicitly examined quality of life[21,41], multiple studies implied that improving psychosocial outcomes would lead to the improvement of quality of life of PWD. Other variables examined focusing on the psychosocial aspect of living with diabetes as it relates to DOC use included shared experience, social support, and empowerment.

Shared Experience. Shared experience was commonly identified.[17,19,21,26,28,29,31-40,42,43,45,47,48,51-54,57-59] Shared experience in the DOC was qualified as (1) a value and role marker for members (DOC users valued those with more diabetes experience[34] with some members taking on mentor-like roles);[35,43,54] (2) a post category that occurred most frequently (27-35% of the time);[39,51] (3) a method of normalization which validated the lived-experience of members[36] and provided comfort resulting in decreased feelings of isolation;[19,21,29,30,36,37] (4) a learning opportunity[21,26,28,29,33-35,54] sometimes gained through humor and venting;[29,41,47] (5) a mode of story-telling;[43,45,52] (6) a pathway toward empowerment;[26,29,34] and (7) a relationship-building process between users[35,53,57] and between users and the wider DOC network.[47] Shared experience appears to underpin activity toward other psychosocial benefits and negative consequences within the DOC.

Social Support. Social support was an overarching multimodal theme. Broadly, social support was identified as helpful during life transitions, such as a new diabetes diagnosis or pregnancy.[30,31,35,37,57] DOC use is positively correlated with social support.[23] Half of posts from adolescent DOC users sought social support from peers.[53] Social support was most commonly subcategorized as informational, emotional, instrumental, or appraisal support (Table 9). While there was occasional overlap, these categories remained distinct across most studies.

Empowerment. Empowerment was reciprocated through a learning and sharing process. High DOC use was associated with feelings of empowerment.[21] As a result, DOC users were more likely to communicate with their health care providers.[22,23] DOC use helped individuals take ownership of their condition, resulting in more active engagement with HCPs.[29] Interaction with the DOC allowed some individuals to question their T2D diagnosis, leading to a subsequent correct T1D diagnosis and treatment regimen.[29] One pathway suggested increased DOC use predicted increased social support, which predicted sense of empowerment.[23]

Behavioral

Behavioral outcomes were discussed across studies of varying methodologic approaches. Motivation and accountability emerged as a subcategory based on frequency of DOC use. The majority of benefits related to DOC use discussed concepts of diabetes self-management in some capacity. Enveloped within the larger category of self-management emerged the subcategory of diabetes self-care.

Motivation and Accountability. The DOC was used as a source for motivation and accountability.[19,22,29,30,32,35,45,47,54] DOC users varied in how they were motivated, some of which included (1) healthy eating or exercise check-ins, (2) interaction with role models who had achieved their weight loss or diabetes management goals, (3) PWD with similar circumstances and goals, and (4) competition.

Diabetes Self-Care. Two studies[21,25] examined the Diabetes Self-Care Inventory Revised tool,[60] while one study[22] used the Diabetes Self-Care Activities measure.[61] Diabetes

Table 8. Benefits and Consequences Related to DOC Use and Diabetes Type.

	Actual or perceived benefits													Actual or perceived consequences								Diabetes type		
	Clinical			Psychosocial							Behavioral							Psychosocial						
					Social support																			
Author	Supplement to clinical care	A1C	HCP support of DOC use	Shared experience	Informational	Emotional	Instrumental	Appraisal	Quality of life	Empowerment	Motivation and accountability	Diabetes management	Community building	Help/ harm	Information quality	Risky behavior	Acute concerns	Emotional/ hostile conflict	Parental outcomes	Privacy	Inactivity	Type 1 diabetes	Type 2 diabetes	Unknown
AlQarni et al[39]				⊙		⊙						⊙												⊙
Arduser[40]				x		x						x										x	x	
Balkhi et al[17]		⊙		⊙																		⊙		
Balkhi et al[18]		⊙		⊙															⊙			⊙		
Beguerisse-Diaz et al[41]					▪								▪					▪				▪	▪	
Bond et al[42]				x	x							x			x									x
Brady et al[28]				x								x	x							x		x	x	
Brady et al[29]				x	x	x		x		x	x		x				x					x	x	
Browne et al[19]	⊙			⊙	⊙	⊙					⊙	⊙										⊙	⊙	
Chen[57]	⊙				⊙	⊙						⊙										⊙		
Chomutare, 2013[56]												▪							▪		▪	▪	▪	
Chomutare 2013[56]		▪						▪													▪		▪	
Chomutare, 2012[57]		▪																			▪		▪	
Cole et al[20]															⊙									⊙
Dias, 2012[58]					▪																			▪
Fergie et al[30]				x							x	x												x
Fergie et al[31]						x		x				x	x		x		x	x						x
Gilbert[32]				x	x	x	x	x			x	x	x									x		
Greene[43]				x	x	x	x	x				x	x		x									x
Hastings[33]				x	x	x	x	x				x	x			x						x		
Hoffman-Goetz[44]	x				x							x			x								x	
Huh[45]				x	x	x	x	x			x							x				x		
Kelly[46]												x			x									x
Koteyko and Hunt[47]	x			x		x		x			x	x	x									x	x	
Lewis[48]				x	x	x						x											x	
Libreri[59]				x	x	x	x					x	x											x
Litchman et al[34]	x			x	x	x	x	x		x		x	x		x		x	x				x		
Litchman et al[21]	⊙	⊙	⊙		⊙	⊙	⊙		⊙	⊙		⊙	⊙									x	x	
Litchman et al[49]													x											x
Litchman et al[50]		x			x	x	x	x	x			x	x									x		
Liu et al[60]																						x	x	
Lu et al[61]					⊙	⊙						⊙						⊙						⊙
Mogi et al[51]				▪	▪	▪						▪										▪	▪	
Nelakurthi et al[22]	⊙	⊙		⊙				⊙		⊙	⊙	⊙										⊙	⊙	
Newman et al[35]				x	x	x	x	x			x	x	x					x		x				x
O'Kane et al[36]	x			x	x		x	x				x										x	x	
Oh and Lee[23]	⊙				⊙	⊙	⊙			⊙														⊙
Oser et al[52]				x	x	x									x				x			x		
Rasmussen et al[37]				x	x	x		x					x							x		x		
Ravert et al[53]				x	x	x		x				x				x						x		
Sparud-Lundin et al[38]				x	x	X																x		
Sparud-Lundin et al[24]					⊙	⊙		⊙					⊙									⊙		
Troncone et al[58]				▪		▪						▪	▪									▪		
Vaala et al[25]		⊙										⊙	⊙									⊙		
Van Berkel et al[26]				⊙	⊙	⊙				⊙		⊙			⊙							⊙	⊙	
White et al[27]	⊙				⊙	⊙	⊙					⊙		⊙										⊙
Zhang et al[54]				x	x	x					x	x	x											x

⊙, quantitative study; x, qualitative study; ▪, social network analysis or text mining study.

Table 9. Types of Social Support.

informational support	• Informational support was attained by DOC users through peers with experiential and academic knowledge • Allowed DOC users to learn about diabetes research things that their HCP may not know or have time to address in appointments, and things they do not feel comfortable asking kin • Translated to members self-evaluating and enhancing their diabetes self-management techniques
Emotional support	• Emotional support aids members ability to cope • Serves as an outlet for frustration • Establishes/strengthens members' sense of belonging and community • Older adults feel emotionally supported through asynchronous posts that may not be directed toward them • May not be perceived as comprehensive for all users • Can lead to Some DOC better in-person relationships and personal networks on Facebook than kin • Lead members to meet up with someone from the DOC offline
Appraisal support	• Appraisal support prompts self-reflection, encouragement, and reciprocity within and between DOC members • An aspect of patient empowerment, allowing patients to transcend their role as passive recipients of expert care to a proactive and empowered agent in their own health
Instrumental support	• Provided through financial and diabetes-related technology and equipment donations • Virtual gifts • Sharing of noncommunity resources

self-care scores were higher (indicating more self-care) in adult[21] and adolescent[25] DOC users when compared to those not using the DOC. Diabetes self-care was also positively correlated with DOC use.[21] Specific self-care tasks, such as healthy eating, exercising, checking glucose levels and taking insulin were more frequently self-reported in DOC users compared to nonusers.[22] Qualitatively, the DOC was identified as an important factor in supporting diabetes self-care.[34,40,47,57] DOC users used peers to problem-solve by crowdsourcing diabetes related issues and concerns.[25,30,41]

Community Building

Community building motivated DOC participation,[33,43] as expressed through linguistic solidarity,[47,58] and as facilitated by identity construction and validation.[33,47,54] To keep some individuals more closely tied to their network, some DOC users engaged with more than one DOC platform, deepening relationships and access to support.[35] Engaging in a DOC required effort, such as identifying supportive contacts or nudging existing contacts to be healthier.[35] While financial compensation for product sponsorship was mentioned for some bloggers,[41] no studies commodified DOC participation in terms of work or labor, nor did they examine changing community dynamics if and when key DOC users choose to leave, decrease activity, or expire.

The curation of online diabetes-related content was identified as a beneficial aspect of DOC use.[28,41,43,47,59] Several studies indicated that adult[21,27,28,34,41] and adolescent[25,53] DOC users participated to help others. This help occurred even when the DOC user didn't need help in return,[34] suggesting altruism. Efforts to help others sometimes resulted in patient-driven innovation[27,41] and in personal and public advocacy efforts.[43,52] DOC users desired lifelong relationships with peers.[49]

4. Research Question 4: What actual or perceived negative consequences are associated with organic DOC use?

Actual and perceived negative consequences were minimal and were categorized as help or harm, information quality, risky behavior, acute concerns, psychosocial, privacy and inactivity.

Help or Harm

Using similar questions to the Pew Research Center's Internet and American Life Project,[63] two studies examined how helpful or harmful the DOC is.[21,27] The DOC was reported as being helpful 38-70% of the time. Conversely, only 0.07-1.8% of DOC users reported the DOC causing minor harm.[21,27] This harm was further characterized in one study[27] as glucose information overload which related to technology, and not community interactions. In one study, some DOC users weren't sure if help (27.3%) or harm (45%) had taken place.[21]

Information Quality

Misinformation was uncommon in online forums and blogs.[20,26,44,46,52] Potentially misleading and misinformation in DOC posts ranged from 0-9% and were characterized as unlikely to lead to untoward effects (Table 10). A self-policing process among DOC users to dilute misinformation was described.[20,34] Some DOC users were forthright in notifying others that their experience may differ from the experiences of others, making posts more trustworthy.[34,42] Many DOC users underwent a vetting process to determine accuracy and quality of information found within the DOC,[30,34,42] which sometimes included contacting HCPs.[34] Sharing and "like"

Table 10. Quality of Content in DOC Posts.

Author	Reviewer	Number and type of posting (platform)	Potentially misleading or misinformation, N (%)
Cole et al[20]	8 physicians 9 PWD	113 posts (on 3 online forums)	1 (0.9)
Hoffman-Goetz et al[44]	Researchers	35 posts (on an online forum of retired Canadians with T2D)	3 (8.6)
Kelly et al[46]	5 diabetologists	61 original posts	0 (0)
		242 responses/comments (on an online forum)	6 (2.5)
Oser et al[52]	2 physicians	140 blog posts	0 (0)
		663 comments (on T1D caregiver blogs)	2 (0.3)
Van Berkel et al[26]	1 researcher 1 pharmacist	1130 posts (from 3 online message boards)	8 (0.5) "Incorrect" 80 (7.1) "Disputable"

features are used by some DOC users to highlight quality information.[47]

Risky Behavior and Acute Concerns

The DOC was sometimes used to explore risky behavior, such as alcohol or drug use and diabulimia. Adolescents[53] and Facebook DOC users[43] wanted to learn about how risky behaviors might affect their diabetes. While use of the DOC could be helpful to some with diabulimia, it could threaten recovery in others.[33] There were mixed reports of the DOC being used for acute concerns. While Brady[29] did not identify the DOC being used for acute concerns, others did.[30,34] When offline support was unavailable or not helpful, some individuals would turn to the DOC to obtain timely assistance.[30,34] Although, during acute situations, DOC users would refer individuals to a HCP.[34]

Psychosocial

As described above, the DOC was used as a way to provide and receive psychosocial support. However, there were instances in which negative aspects were reported, though they were infrequent. Topical areas included emotional or hostile posts and parent outcomes.

Avoidance of Posts with Emotional or Hostile Conflict. Some DOC users reported purposefully avoiding posts that were excessively emotional.[30,34,35] There were also instances of infighting among DOC users resulting in negative discussions about T1D and T2D that appeared to be rooted in misconceptions and possibly stigmatizing attitudes.[34,41] This infighting sometimes drove individuals away from the DOC, at least temporarily.[34] One study identified Twitter DOC users wishing diabetes upon individuals who didn't have diabetes in response to stigmatizing comments.[41] There are differences in how individuals present themselves based on platform. For example, hate comments were not identified in diabetes vlogs on YouTube.[45] In one study, DOC users presented themselves as more composed on Facebook compared to other DOC platforms.[35]

Parental Outcomes. DOC use by parents has been associated with parental hypoglycemia fear and parental stress frequency,[17] however, causation could not be determined. It is unknown if parents with hypoglycemia fear or increased parental stress frequency are more likely to engage in the DOC for support or other factors, or if DOC use might increase hypoglycemia fear and parental stress frequency. Similarly, a social network analysis identified that parents of children with diabetes struggled the most among online forum users, although did not characterize this further.[55]

Privacy

The DOC was often viewed as a public space and DOC users shared information in a variety of ways. Some DOC users were more willing to share personal health information in a live chat session where data wasn't stored, in a private group, or filtered personal information in more public spaces.[28,35] Some DOC users were intentionally selective about which DOC platforms they would share personal information with emotional content[31,35,37] while others shared openly among "friends," forgetting that strangers could also view the information[28] or that posts could automatically update on other social networking profiles.[35] Very few studies mentioned lurking,[32,34,35,46] a concept used to describe DOC users who passively engage (ie, read content) in DOC activity generated by others, but do not actively participate (ie, originate or comment on posts). While lurkers may be able to obtain support without providing personal information, Newman[35] suggests DOC users could not be emotionally supported unless they were willing to post their struggles, which may conflict with desires for privacy. In contrast, one study described DOC users who could be emotionally supported by reading content generated by others,[34] supporting the notion that DOC users can maintain privacy as passive participants.

Inactivity

There was very little information about inactivity by means of never starting or stopping DOC use. Mogi[51] found that more than half of DOC communities on Google+ were inactive. While the DOC was used during times of need for additional social support,[30,31,37] no studies examined DOC use or inactivity as it related to support from personal networks. Only one study examined why PWD would not use the DOC. In this study focused on adolescents, the most common reasons reported for not using DOCs were because there was no identified need or problem warranting DOC use, no desire to talk about diabetes, or a belief that social networking should not be used for diabetes.[25]

5. Research Question 5: What gaps exist in the current DOC literature?

Answering this research question was an iterative process conducted in which the research team members, comprised of clinicians, PWD, caregivers to children with diabetes, and researchers; discussed content and methodological areas of weakness within the body of research reviewed. Five gaps in knowledge emerged: (1) lack of DOC definition, (2) description of DOC users and platforms, (3) use of multiple DOC platforms, (4) research methodology, and (5) privacy. Findings and recommendations for future research are described in Table 11.

Discussion

This scoping review aimed to systematically map and synthesize existing published research focused on organic DOCs and to identify knowledge gaps. We identified a global collection of studies with a variety of methodologies and outcome measures. Research in this topical area is rapidly emerging, however, to date, is relatively descriptive. In addition, there is no consensus of terminology across research in this content area.

Given the lack of consensus on a DOC definition in the included studies, we propose a new definition that reflects our findings: *The "DOC" is a user-generated term that encompasses people affected by diabetes who engage in online activities to share experiences and support in siloed or networked platforms*. This definition not only lends credence to the term used by communities of interest, but also recognizes the multifariousness of DOCs.

Most studies we reviewed focused on a singular DOC platform without identifying doing so as a methodological limitation. We can assume their epistemological understanding of the DOC is monolithic. A significant finding of this study is that there is no singular DOC, but several distinct groups, resulting in multiple DOCs. Recurrent users were identified by some studies, but not all. A community element may be necessary to understand long-term benefits and consequences of DOC use. Future research on DOC activity and outcomes would benefit from the use of participatory frameworks, such as including users in the design and parameter-setting stages to not only capture a community element, but also increase the social validity and usability of the knowledge produced by the work.[64]

There was also a general lack of participant diversity accounted for in the studies. This lack of diversity was found among DOC users by race, education, and diabetes type, though DOC research in Hispanic populations is underway.[65] Although T2D makes up the majority of all types of diabetes,[66] most research identifying diabetes type was focused on T1D, suggesting those with T1D may be more inclined to use the DOC. Perhaps individuals with T1D specifically seek out the DOC because it is more challenging to identify a peer offline. Other types of diabetes, such as latent autoimmune diabetes of adulthood, were only described in two studies[21,34] and warrant further examination given the higher possible rates of misdiagnosis.[67] It is possible that individuals with diverse backgrounds, lower income, or T2D may initially come to the DOC, but do not stay because they are unable to identify relatable peers. Individuals with T2D may experience stigma as a result of hostile posts between those with T1D and T2D[34] or "humorous" posts that may be perceived as stigmatizing.[41] There were no studies focused on DOC users who have left the DOC, although one article illuminated why adolescents may not be using the DOC.[25] Future research should carefully examine attrition rates,[68] including reasons, such as adverse outcomes and disinterest. This examination may help to characterize for whom the DOC is most beneficial.

All studies discussed or measured benefits and consequences to DOCs participation in some capacity. One of those measures was A1C. A1C was neutrally or beneficially associated with DOC use. In a randomized control trial of adolescents, A1C was reduced in researcher-developed DOC groups when compared to control.[69] Similarly, in a retrospective cross-sectional study of adolescents and young adults, A1C improved using a researcher-developed DOC group.[70] Therefore, there may be utility in both organic and researcher-driven DOCs. Given that parental stress is linked to worsening A1C in children with diabetes,[71] perhaps the DOC provides a protective factor in neutralizing A1C as parents can solicit and receive support. Among adults, engagement in the DOC may influence both behavioral and psychosocial barriers to self-care, resulting in safer glycemic levels. Alternatively, DOC users may be motivated by social comparison[72,73] or influenced by social contagion.[74] Finally, information from peers may provide autonomy support75 when family and friends are not helpful.[76] Lack of biophysical measures of A1C may affect reliability of data. However, consistency between self-reported A1C and registry data has been established.[77,78]

Shared experience was the most frequently mentioned topic across all studies reviewed. Shared experiences provided DOC users with a sense of normalcy, validating the lived experiences of PWD. DOC users report higher ratings on quality of life measures than non-DOC users, suggesting that DOC use influences users in ways that extend beyond diabetes-specific outcomes. Empowerment was described as an individual measure leading to positive self-management

Table 11. Gap Analysis.

Gaps	Our findings	Recommendations for future research
Gap 1. DOC definition	There is no clear definition of the DOC.	Seek to identify a definition that includes consensus among multiple stakeholders. In the discussion section we propose a new definition.
Gap 2. DOC users and platforms	It is difficult to estimate the size of the DOC (ie, How many DOC platforms are there? How many DOC users are there?) given the limited research in this area. In addition, we don't fully understand who is using the DOC. Demographic information is inherently difficult to identify in retrospective analysis of DOC data. Of those studies that did identify demographic information, the majority included well-educated White respondents living with or impacted by T1D as a caregiver. Few studies, mostly in isolated geographic locations, examined a cross-section of individuals affected by diabetes to identify if they were DOC users. Our findings suggest the DOC can provide a variety of benefits with little negative consequences. However, the nature of the research identified in this review did not examine individuals who may have used the DOC, but stopped due to disinterest, untoward effects, or inability to identify peers they can relate to.	Seek to identify all of the DOC platforms that make up the DOC. Seek to better characterize DOC users, including characteristics of those who use the DOC for a brief and single episode, those who use the DOC off and on, and those who use the DOC regularly. Understanding the characteristics of those who are the most and least likely benefit from DOC use should also be identified. Seek to identify why diverse individual with diabetes, including those with T2D, may not being using DOC. It is possible that the DOC platforms that are being used by diverse individuals are not being studied. Explore HCP perception of DOC use among their patients to identify possible negative consequences of DOC use.
Gap 3. Multiple DOC platforms	Studies to date describe micro-communities that encompass the DOC, not a unified DOC that networks all DOC users together. For example, examining only online forums or only Twitter. With the interoperability of social networking sites, it is possible that DOC use by individual users may span multiple types of DOC platforms. Conversely, it is possible that there are there are communities that are actually siloed and not interconnected.	Exploring what micro-community DOC individuals are using will help to understand how vast their diabetes network is. Understanding the type of DOC platform that is most beneficial for different users is critical to translating DOC use into clinical practice.
Gap 4. Research methodology	There were no experimental studies in which the DOC was used as an intervention. Therefore, it is unknown if the DOC has any effect—causal or otherwise—on clinical, behavioral, or psychosocial outcomes. Specifically it is unknown if diabetes distress or diabetes-related stigma are affected by DOC use because it hasn't been measured. There were no studies that described their examination and interpretation of emojis or memes, which is commonly used in social media. Studies to date do not explore a longitudinal analysis of DOC use other than describing some may come back to use the DOC at times of increased need.	Future research should investigate thoughtfully designed DOC interventions to evaluate effects on health outcomes. Using community-based participatory methods may enhance the feasibility and effectiveness of the interventions. Processes to manage emojis and memes should be undertaken. Longitudinal analysis of DOC users may reveal positive and negative implications of ongoing online peer interaction.
Gap 5. Privacy	No studies described DOC use within a personal network that may include multiple DOC users. For example, family affected by diabetes with more than one DOC user. Within a personal network of multiple DOC users, each user could be engaging in the DOC for different reasons. It is possible that some DOC users may not want their family members to see their posts, which may include venting, exploration of risky behavior, or other factors they wish to keep private. Children with diabetes may have feelings about their parents posting about their diabetes in the DOC that has yet to be explored. No studies described how DOC data may be used to make health care or other decisions. For example, an insurance payer or employer. No studies described how new DOC users are able to access private DOC groups. As new DOC users join private groups, this may leave existing users feeling as if their privacy has been violated.	Examining digital stewardship or lack thereof among personal networks and the desire for joint media engagement should be explored. Explore the policy implications of DOC data being used by insurance payers or employers. Investigate general accessibility across DOC platforms.

behaviors. Studies did not report collective empowerment of multiple DOC users as it relates to advocacy or activism. While there were multiple psychosocial benefits noted related to DOC use, no studies examined diabetes distress, a known predictor of self-management behaviors.[3]

Misinformation was uncommon across several of the studies reviewed. In the context of a community, DOC users appear to be obtaining relevant and credible information as suggested by Apomediation Theory.[79,80] In some instances, the DOC corrected misinformation in the online community using a self-policing model. Further, DOC users reported misinformation originating from HCPs. For example, providing information that led someone who was misdiagnosed to a correct diabetes diagnosis—a more common occurrence now that we understand nearly half of T1D cases are diagnosed after age 30.[67] While professional organizations can successfully debunk misinformation online,[81] they can mislead as well.[82]

Consequences to DOC use were minimal. However, in certain populations, such as those with diabulemia, DOC use may not be beneficial given that it may threaten recovery.[33] As such, DOC use may not be beneficial for all. In some instances, interactions akin to cyberbullying did occur, which amplified negative consequences, however, this was not common. Notable, some DOC users were unsure if they had been helped or harmed by DOC use,[21] which warrants further study.

Clinical Implications

Overall, DOC use suggests a variety of benefits with low reports of negative consequences. Currently, 1 in 3 diabetes educators recommend DOC participation to their patients.[83] However, we do not know if and how frequently other HCPs (ie, pediatric and adult endocrinologists, primary care providers) recommend DOCs. DOC users are interested in having HCPs read through DOC postings in order to enhance understanding of living with diabetes and the value the DOC has for its users. In the United States, 73% of diabetes educators are engaged in the DOC either actively or passively.[83] The DOC, with minimal costs associated with use, is a relatively accessible solution to the professional recommendations for peer support.[8-10]

Limitations

It is possible that our search strategy did not identify all articles examining organic DOCs. Searching other databases may have yielded other studies that would have met inclusion criteria. We did not seek to identify how HCPs are using the DOC to interact, learn from, or provide education to PWD. We only included articles written in English. Conference proceedings, which may have provided additional insight to this review, were excluded. While we did not explore the interaction between HCPs and PWD, research suggests HCP-patient interaction on social media is an effective and naturally cost-effective intervention to promote health.[84]

Conclusion

This scoping review maps existing research focused on peer-to-peer interaction within organic DOCs. DOCs are relatively accessible resources and spaces for peer support activity that appear to be beneficial to users with minimal harm reported. Future experimental research is needed to understand the impact of DOC use on health outcomes.

Abbreviations

A1C, hemoglobin A1C; CMSS, computer-mediated social support; CWD, children with diabetes; DOC, diabetes online community; FDA, Food and Drug Administration; HCP, health care provider; LADA, Latent Autoimmune Diabetes of Adults; M, mean; PWD, people with diabetes; Q&A, question and answer; SD, standard deviation; T1D, type 1 diabetes; T2D, type 2 diabetes.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project is supported by a research award from the American Association of Diabetes Educators.

Supplemental Material

Supplemental material for this article is available online.

ORCID iDs

Heather R. Walker https://orcid.org/0000-0003-1134-5779
Ashley H. Ng https://orcid.org/0000-0002-8261-6006
Sarah E. Wawrzynski https://orcid.org/0000-0003-2756-2583
Sean M. Oser https://orcid.org/0000-0002-9640-3087
Tamara K. Oser https://orcid.org/0000-0002-0405-3420

References

1. Hilliard ME, Sparling KM, Hitchcock J, Oser TK, Hood KK. The emerging diabetes online community. *Curr Diabetes Rev*. 2015;11:261-272.
2. Tai-Seale M, McGuire TG, Zhang W. Time allocation in primary care office visits. *Health Serv Res*. 2007;42:1871-1894.
3. Nicolucci A, Kovacs Burns K, Holt RI, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabet Med*. 2013;30:767-777.
4. Fisher L, Mullan JT, Arean P, Glasgow RE, Hessler D, Masharani U. Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. *Diabetes Care*. 2010;33:23-28.

5. Liu NF, Brown AS, Younge MF, Guzman SJ, Close KL, Wood R. Erratum: stigma in people with type 1 or type 2 diabetes. *Clin Diabetes*. 2017;35:27-34. Clin Diabetes. 2017;35(4):262.
6. Fox S. *Peer-to-peer Healthcare 2011*. Washington, DC: Pew Research Center.
7. Rideout V, Fox S. *Digital Health Practices, Social Media Use, and Mental Well-being among Teens and Young Adults in the US*. Hopelab and Well Being Trust; 2018.
8. Beck J, Greenwood DA, Blanton L, et al. 2017 National standards for diabetes self-management education and support. *Diabetes Educ*. 2017;43:449-464.
9. American Diabetes Association. Lifestyle management: standards of medical care in diabetes-2018. *Diabetes Care*. 2018;41(suppl 1):S38-S50.
10. Powers MA, Bardsley J, Cypress M, et al. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. *Clin Diabetes*. 2016;34:70-80.
11. Warshaw H, Edelman D. Building bridges through collaboration and consensus: expanding awareness and use of peer support and peer support communities among people with diabetes, caregivers, and health care providers. *J Diabetes Sci Technol*. 2018:1932296818807689.
12. Armstrong R, Hall BJ, Doyle J, Waters E. "Scoping the scope" of a Cochrane review. *J Public Health*. 2011;33:147-150.
13. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8:19-32.
14. Babineau J. Product review: covidence (systematic review software). *J Can Health Libr Assoc*.2014;35:68-71.
15. Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLOS MED*. 2009;6:e1000097.
16. Joanna Briggs Institute. *Joanna Briggs Institute Reviewers' Manual: 2014 Edition*. Australia: Joanna Briggs Institute; 2014.
17. Balkhi AM, Reid AM, McNamara JP, Geffken GR. The diabetes online community: the importance of forum use in parents of children with type 1 diabetes. *Pediatr Diabetes*. 2014;15:408-415.
18. Balkhi AM, Olsen B, Lazaroe L, Silverstein J, Geffken GR. Paging Dr. Google: parents' report of internet use for type 1 diabetes management. *Diabetes Care*. 2015;38:e18-e19.
19. Browne JL, Bennet A, Halliday JA, Holmes-Truscott E, Speight J. Diabetes Peer Support in Australia: A National Survey. Melbourne, Australia: Diabetes Victoria; 2016.
20. Cole J, Watkins C, Kleine D. Health advice from Internet discussion forums: how bad is dangerous? *J Med Internet Res*. 2016;18.
21. Litchman ML, Edelman LS, Donaldson GW. Effect of diabetes online community engagement on health indicators: cross-sectional study. *J Med Internet Research Diab*. 2018;3:e8.
22. Nelakurthi AR, Pinto AM, Cook CB, et al. Should patients with diabetes be encouraged to integrate social media into their care plan? *Fut Sci OA*. 2018;4:Fso323.
23. Oh HJ, Lee B. The effect of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. *Health Commun*. 2012;27:30-41.
24. Sparud-Lundin C, Ranerup A, Berg M. Internet use, needs and expectations of web-based information and communication in childbearing women with type 1 diabetes. *BMC Med Inform Decis Mak*. 2011;11:49.
25. Vaala SE, Hood KK, Laffel L, Kumah-Crystal YA, Lybarger CK, Mulvaney SA. Use of commonly available technologies for diabetes information and self-management among adolescents with type 1 diabetes and their parents: a web-based survey study. *Interact J Med Res*. 2015;4:e24.
26. van Berkel JJ, Lambooij MS, Hegger I. Empowerment of patients in online discussions about medicine use. *BMC Med Inform Decis Mak*. 2015;15:24.
27. White K, Gebremariam A, Lewis D, et al. Motivations for participation in an online social media community for diabetes. *J Diab Sci Technol*. 2018;12:712-718.
28. Brady E, Segar J, Sanders C. "I always vet things": navigating privacy and the presentation of self on health discussion boards among individuals with long-term conditions. *J Med Internet Res*. 2016;18:e274.
29. Brady E, Segar J, Sanders C. Accessing support and empowerment online: the experiences of individuals with diabetes. *Health Expect*. 2017;20:1088-1095.
30. Fergie G, Hilton S, Hunt K. Young adults' experiences of seeking online information about diabetes and mental health in the age of social media. *Health Expect*. 2016;19:1324-1335.
31. Fergie G, Hunt K, Hilton S. Social media as a space for support: young adults' perspectives on producing and consuming user-generated content about diabetes and mental health. *Soc Sci Med*. 2016;170:46-54.
32. Gilbert K, Dodson S, Gill M, McKenzie R. Online communities are valued by people with type 1 diabetes for peer support: how well do health professionals understand this? *Diab Spec*. 2012;25:180-191.
33. Hastings A, McNamara N, Allan J, Marriott M. The importance of social identities in the management of and recovery from "Diabulimia": a qualitative exploration. *Addict Behav Rep*. 2016;4:78-86.
34. Litchman ML, Rothwell E, Edelman LS. The diabetes online community: older adults supporting self-care through peer health. *Patient Educ Couns*. 2017;6:6.
35. Newman MW, Lauterbach D, Munson SA, Resnick P, Morris ME. It's not that I don't have problems, I'm just not putting them on Facebook: challenges and opportunities in using online social networks for health. In: Proceedings of the ACM Conference on Computer-Supported Cooperative Work. New York, NY: Association for Computing Machinery; 2011:341-350.
36. O'Kane AA, Park SY, Mentis H, Blandford A, Chen YA. Turning to peers: integrating understanding of the self, the condition, and others' experiences in making sense of complex chronic conditions. *Comput Supp Coop W J Collab Comput*. 2016;25:477-501.
37. Rasmussen B, Dunning P, O'Connell B. Young women with diabetes: using Internet communication to create stability during life transitions. *J Clin Nurs*. 2007;16:17-24.
38. Sparud-Lundin C, Ohrn I, Danielson E. Redefining relationships and identity in young adults with type 1 diabetes. *J Adv Nurs*. 2010;66:128-138.
39. AlQarni ZA, Yunus F, Househ MS. Health information sharing on Facebook: an exploratory study on diabetes mellitus. *J Infect Public Health*. 2016;9:708-712.
40. Arduser L. Warp and weft: weaving the discussion threads of an online community. *J Tech Writ Commun*. 2011;41:5-31.

41. Beguerisse-Díaz M, McLennan AK, Garduño-Hernández G, Barahona M, Ulijaszek SJ. The "who" and "what" of #diabetes on Twitter. *Digital Health*. 2017;3:2055207616688841.
42. Bond CS, Ahmed OH. Can I help you? Information sharing in online discussion forums by people living with a long-term condition. *J Innov Health Inform*. 2016;23:620-626.
43. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *J Gen Int Med*. 2011;26:287-292.
44. Hoffman-Goetz L, Donelle L, Thomson MD. Clinical guidelines about diabetes and the accuracy of peer information in an unmoderated online health forum for retired persons. *Inform Health Soc Care*. 2009;34:91-99.
45. Huh J, Liu LS, Neogi T, Inkpen K, Pratt W. Health vlogs as social support for chronic illness management. *ACM Trans Comput Hum Inter*. 2014;21:1-31.
46. Kelly W, Connolly V, Bilous R, et al. Reader beware: diabetes advice on the web. *Pract Diab Int*. 2002;19:108-110.
47. Koteyko N, Hunt D. Performing health identities on social media: an online observation of Facebook profiles. *Discourse Context & Media*. 2016;12:59-67.
48. Lewis JA, Gee PM, Ho C-LL, Miller LMS. Understanding why older adults with type 2 diabetes join diabetes online communities: semantic network analyses. *JMIR Aging*. 2018;1:e10649.
49. Libreri C, Graffigna G. Mapping online peer exchanges on diabetes. *Neuropsychol Trends*. 2012;12:125-134.
50. Litchman ML, Snider C, Edelman LS, Wawrzynski SE, Gee PM. Diabetes online community user perceptions of successful aging with diabetes: analysis of a# DSMA Tweet Chat. *JMIR Aging*. 2018;1:e10176.
51. Litchman ML, Lewis D, Kelly LA, Gee PM. Twitter analysis of #OpenAPS DIY artificial pancreas technology use suggests improved A1C and quality of life. *J Diab Sci Technol*. 2018:1932296818795705.
52. Mogi Y, Abedin T, Ahmed S, et al. Social networking sites for peer-driven health communication: diabetes-related communities in Google+. *Diabetol Int*. 2017;8:323-327.
53. Oser TK, Oser SM, McGinley EL, Stuckey HL. A novel approach to identifying barriers and facilitators in raising a child with type 1 diabetes: qualitative analysis of caregiver blogs. *JMIR Diabetes*. 2017;2:e27.
54. Ravert RD, Hancock MD, Ingersoll GM. Online forum messages posted by adolescents with type 1 diabetes. *Diabetes Educ*. 2004;30:827-834.
55. Zhang Y, He D, Sang Y. Facebook as a platform for health information and communication: a case study of a diabetes group. *J Med Syst*. 2013;37:9942.
56. Chomutare T, Arsand E, Fernandez-Luque L, Lauritzen J, Hartvigsen G. Inferring community structure in healthcare forums. An empirical study. *Methods Inf Med*. 2013;52:160-167.
57. Chomutare T., Årsand E., Hartvigsen G. (2012, August). Temporal community structure patterns in diabetes social networks. In Proceedings of the 2012 International Conference on Advances in Social Networks Analysis and Mining (ASONAM 2012) (pp. 745-750). IEEE Computer Society.
58. Dias A, Chomutare T, Botsis T. Exploring the community structure of a diabetes forum. *Studies in Health Technology and Iinformatics*. 2012;180:833-837.
59. Chen AT. Exploring online support spaces: using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Educ Couns*. 2012;87:250-257.
60. Liu Y, Mei, Hanauer DA, Zheng K, Lee JM. Use of social media in the diabetes community: an exploratory analysis of diabetes-related tweets. *JMIR Diabetes*. 2016;1(2):e4.
61. Lu Y, Wu Y, Liu J, Li J, Zhang P. Understanding health care social media use from different stakeholder perspectives: a content analysis of an online health community. *J Med Internet Res*. 2017;19(4):e109.
62. Troncone A, Cascella C, Chianese A, Iafusco D. Using computerized text analysis to assess communication within an Italian type 1 diabetes Facebook group. *Health Psychol Open*. 2015;2:2055102915615338.
63. Weinger K, Butler HA, Welch GW, La Greca AM. Measuring diabetes self-care: a psychometric analysis of the self-care inventory-revised with adults. *Diabetes Care*. 2005;28:1346-1352.
64. Toobert DJ, Hampson SE, Glasgow RE. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. *Diabetes Care*. 2000;23:943-950.
65. Fox S. The Social Life of Health Information, 2011. Washington, DC: Pew Internet & American Life Project; 2011.
66. Hammel J, McDonald KE, Frieden L. Getting to inclusion: people with developmental disabilities and the Americans with disabilities act participatory action research consortium. *Inclusion*. 2016;4:6-15.
67. Greenwood DA, Litchman ML, Ng AH, et al. Development of the intercultural diabetes online community research council: codesign and social media processes. *J Diabetes Sci Technol*. 2019:1932296818818455.
68. Centers for Disease Control and Prevention. *National Diabetes Statistics Report, 2017*. Atlanta, GA: Centers for Disease Control and Prevention; 2017.
69. Thomas NJ, Jones SE, Weedon MN, Shields BM, Oram RA, Hattersley AT. Frequency and phenotype of type 1 diabetes in the first six decades of life: a cross-sectional, genetically stratified survival analysis from UK Biobank. *Lancet Diabetes Endocrinol*. 2018;6:122-129.
70. Eysenbach G. The law of attrition. *J Med Internet Res*. 2005;7:e11.
71. Petrovski G, Zivkovic M. Impact of Facebook on glucose control in type 1 diabetes: a three-year cohort study. *JMIR Diabetes*. 2017;2:e9.
72. Petrovski G, Zivkovic M. Are we ready to treat our diabetes patients using social media? Yes, we are. *J Diab Sci Technol*. 2018:1932296818795441.
73. Eilander MMA, Snoek FJ, Rotteveel J, et al. Parental diabetes behaviors and distress are related to glycemic control in youth with type 1 diabetes: longitudinal data from the DINO study. *J Diab Res*. 2017;2017:1462064.
74. Martinez W, Wallston KA, Schlundt DG, et al. Patients' perspectives on social and goal-based comparisons regarding their diabetes health status. *BMJ Open Diab Res Care*. 2018;6:e000488.
75. Festinger L. A theory of social comparison processes. *Hum Relat*. 1954;7:117-140.
76. Aral S, Nicolaides C. Exercise contagion in a global social network. *Nat Commun*. 2017;8:14753.
77. Lee AA, Piette JD, Heisler M, Rosland AM. Diabetes distress and glycemic control: the buffering effect of autonomy support

from important family members and friends. *Diabetes Care*. 2018;41:1157-1163.

78. Helgeson VS, Mascatelli K, Reynolds KA, Becker D, Escobar O, Siminerio L. Friendship and romantic relationships among emerging adults with and without type 1 diabetes. *J Pediatr Psychol*. 2015;40:359-372.
79. Schneider AL, Pankow JS, Heiss G, Selvin E. Validity and reliability of self-reported diabetes in the atherosclerosis risk in communities study. *Am J Epidemiol*. 2012;176:738-743.
80. Løvaas KF, Cooper JG, Sandberg S, Røraas T, Thue G. Feasibility of using self-reported patient data in a national diabetes register. *BMC Health Serv Res*. 2015;15:553.
81. Eysenbach G. From intermediation to disintermediation and apomediation: new models for consumers to access and assess the credibility of health information in the age of Web2.0. *Stud Health Technol Inform*. 2007;129:162-166.
82. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. *J Med Internet Res*. 2008;10:e22.
83. Vraga EK, Bode L. Using expert sources to correct health misinformation in social media. *Sci Commun*. 2017;39:621-645.
84. Powell D, Keil M, Brenner D, Lim L, Markman EM. Misleading health consumers through violations of communicative norms: a case study of online diabetes education. *Psychol Sci*. 2018;29:1104-1112.
85. Rinker J, Dickinson JK, Litchman ML, et al. The 2017 diabetes educator and the diabetes self-management education national practice survey. *Diabetes Educ*. 2018:0145721718765446.
86. Wu T, Deng Z, Feng Z, Gaskin DJ, Zhang D, Wang R. The effect of doctor-consumer interaction on social media on consumers' health behaviors: cross-sectional study. *J Med Inter Res*. 2018;20:e73.