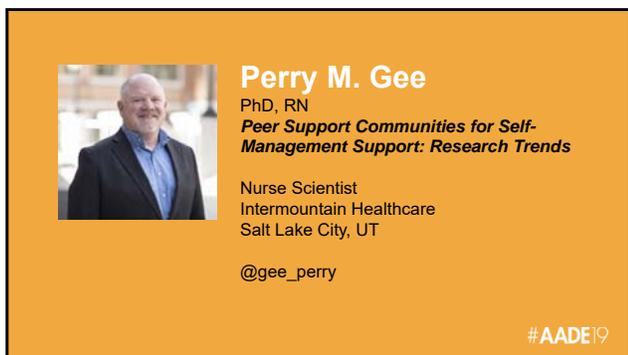
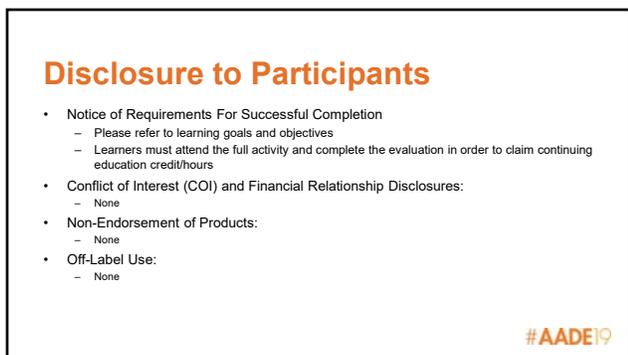




1



2



3



4



5



6

**WILL PEOPLE WITH DIABETES
HAVE ACCESS TO THE DOC?**

#AADE19

7

Susannah Fox
I HELP PEOPLE NAVIGATE HEALTH AND TECHNOLOGY.

Home Writing Research About me Upcoming events

Research

Pew Research Center

<https://susannahfox.com/research/>; <https://www.pewinternet.org/fact-sheet/internet-broadband/> #AADE19

8

Adults and the Internet (2017 & 2018 data)

- **89% of U.S. adults go online.**
- **67% of U.S. adults ages 65+ use the internet.** (Educated adults have highest rates)
- **95% of U.S. adults have a cellphone. 77% of U.S adults own a smartphone.**
- **69% of U.S. adults use some type of social media.**

<https://susannahfox.com/research/>; <https://www.pewinternet.org/fact-sheet/internet-broadband/> #AADE19

9

Teens and the Internet (2018 data)

- Nearly all teens have access to the internet and 45% say they are online "constantly."
- 93% of U.S. teens and young adults (ages 14-22) report using social media.
- 95% of U.S. teens either have a smartphone or access to one.
- 87% of U.S. teens and young adults (14- to 22-year-olds) say they have ever gone online for health information. 64% of U.S. teens and young adults say they have used mobile apps related to health.
- 39% of U.S. teens and young adults say they have gone online to try to find people with health conditions similar to their own.
- One third (33%) of U.S. teens and young adults have successfully connected with health peers online, and 91% of them say the experience was helpful.
- One in five (20%) of U.S. teens and young adults report having connected with health providers online.

(<https://susannahfox.com/research/>; <https://www.pewinternet.org/fact-sheet/internet-broadband/>)



10

WHAT IS AADE'S HISTORY WITH DOC RESEARCH?



11

"Patient Engagement is the Blockbuster Drug of the Century"

The insight of the year goes to **Leonard Kish**, a health IT strategy consultant, for making that statement regarding patient engagement. The corollary to this statement is a game changer: What happens when effective patient engagement becomes the Standard of Care?

Used to determine whether a doctor is liable for medical malpractice. The standard of care is important because it determines the level of negligence required to state a valid cause of action.

109
450
376

(Greenwood & Gee, 2013)



12

Available online at www.sciencedirect.com
 ScienceDirect
 NURSING OUTLOOK
 www.nursingoutlook.org

Exploration of the e-patient phenomenon in nursing informatics

Perry M. Gee, MSN, RN^{a,*}, Deborah A. Greenwood, RN, MEd, CNS, BC-ADM, CDE^b,
 Katherine K. Kim, MPH, MBA^{a,c}, Susan L. Perez, MEd^d,
 Nancy Stagers, PhD, RN, FAAN^e, Hollie A. DeVon, PhD, RN^f

^aForty Five Moore School of Nursing, University of California, Davis, CA
^bDepartment, School of Nursing, University of Maryland, Baltimore, MD
^cHealth Equity Institute, San Francisco State University, San Francisco, CA

AAEDE 13
 THE POINT OF POSSIBLE

(Greenwood & Gee, 2013) #AADE19

13

DIKW Collaboration Model

Collective wisdom is greater than individual wisdom

Building Interactions and Interrelationships

AAEDE 13
 THE POINT OF POSSIBLE

(Greenwood & Gee, 2013) #AADE19

14

Research patientslikeme

- Patients made more informed treatment decisions, managed symptoms more effectively, and coped with side effects of treatments by participating in Patientslikeme.com
- 1323 participants (19%)
- 12% changed providers
- 41% of HIV patients reduced risky behaviors
- 22% of mood disorders patients needed less inpatient care

AAEDE 13
 THE POINT OF POSSIBLE

(Greenwood & Gee, 2013) #AADE19

15

Online Survey of DOC Users

- Demographics
- Health History
- Web 2.0 Application Use
 - Help/Harm
- DOC Benefits
- DOC Intensity Scale
- DOC Engagement
- Internet Social Capital Scale
- SF-12v2
 - Health Related Quality of Life
- Source Credibility
- Self-Care Inventory Revised
 - Diabetes Self-Care Behaviors

AADE15

(Litchman, 2015) #AADE19

16

Conclusion

- The DOC is used as an adjunct to regular diabetes care
- DOC engagement is associated with better glycemic control
- The majority of DOC users reported they had been helped with little harm reported

AADE15

(Litchman, 2015) #AADE19

17

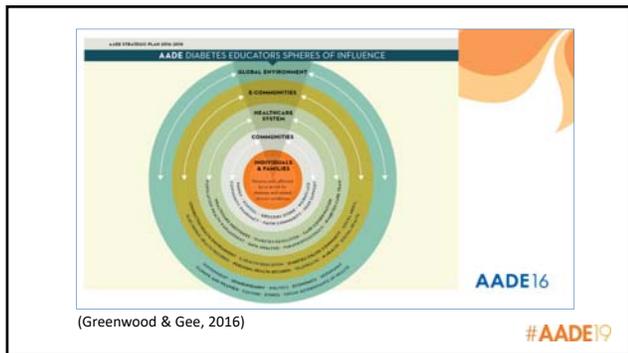
Conclusion Cont'd.

- DOC users had high diabetes self-care and HRQOL scores
- DOC users used the DOC to increase knowledge to improve self-care and for emotional support
- The DOC should be considered for all adults with diabetes

AADE15

(Litchman, 2015) #AADE19

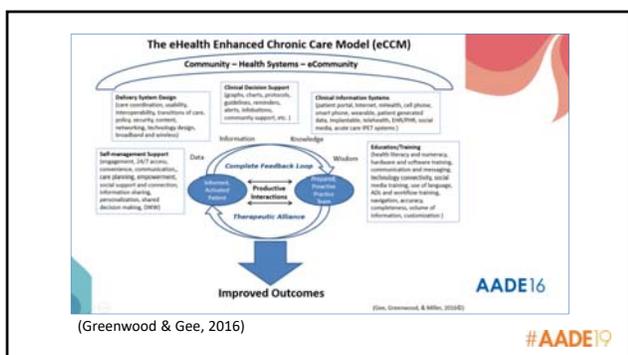
18



19



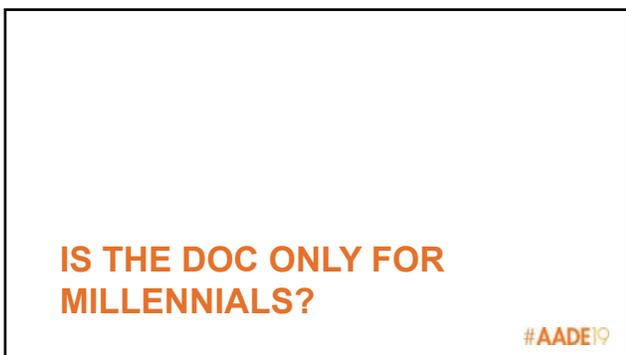
20



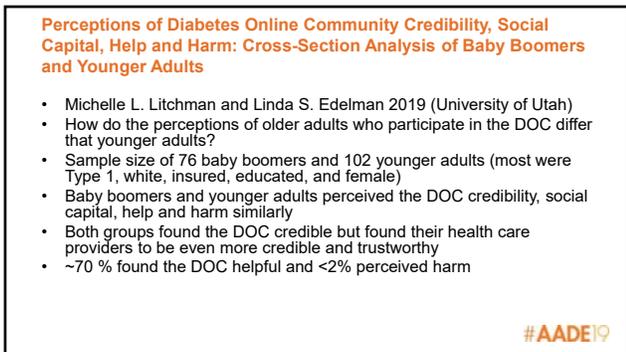
21



22



23



24

JMIR AGING
 Original Paper
Understanding Why Older Adults With Type 2 Diabetes Join Diabetes Online Communities: Semantic Network Analyses
 Jillette Ann Lewis¹, BA, MS; Penny M PhD

¹Department of Human Ecology, University of Utah
 Learning Research and Analytics, Digital Health, is
 a part of the Center for Health Systems Research and
 Analysis, University of Utah, Salt Lake City
²Department of Communication, University of Utah

Corresponding Author:
 Jillette Ann Lewis, BA, MS
 Department of Human Ecology
 University of California, Davis
 1109 Hall Hall
 One Shields Ave.
 Davis, CA, 95616
 United States
 Phone: 1 530 752 3111
 Fax: 1 530 752 3113
 Email: jllewis@ucdavis.edu
Abstract
Background: As individuals age, chronic health difficulties may decrease physical and social well-being. Individuals use



#AADE19

25

Why did older adults join TuDiabetes?

- Total of ~35,000 members in the dataset
- Of that we looked at 1969 individuals who were > 65 y/o and had type 2 diabetes
- Seek information about diabetes
- Help with self-management activities
- Informational and social support
- A community with whom to share
- Women mostly wanted sharing and companionship
- Men mostly wanted general diabetes information and self-management support

#AADE19

26

CAN STUDYING THE DOC HELP US PREDICT HEALTH ISSUES?

#AADE19

27

Tu Diabetes

- Patient Engagement
 - 24.3% responded
 - 96.6 % future research contact
 - 31.7% posted A1C on profile page



(Greenwood & Gee, 2013)

#AADE19

28

INIR RESEARCH PROTOCOLS Xie et al.

Protocol

Predicting Prediabetes Through Facebook Postings: Protocol for a Mixed-Methods Study

Xiaomeng Xu¹, PhD, Michelle L. Lachance², PhD, FNP-BC, FAANP, Perry M Gee^{1,3}, PhD, RN, Wally Wharton⁴, AA, Lori Chouin⁵, RN, John Holman⁶, PharmD, Sankara Subramanian Srinivasan⁷, PhD, MBA

¹Department of Psychology, Idaho State University, Pocatello, ID, United States
²College of Nursing, University of Utah, Salt Lake City, UT, United States
³Nursing Research and Analytics, DePaul Health, San Francisco, CA, United States
⁴School of Business, University of Utah, Salt Lake City, UT, United States
⁵Department of Family Medicine, Idaho State University, Pocatello, ID, United States
⁶David Eccles School of Business, University of Utah, Salt Lake City, UT, United States

Corresponding Author:
 Xiaomeng Xu, PhD
 Department of Psychology
 Idaho State University
 921 S 8th Avenue, Stop #112
 Pocatello, ID 83209
 United States
 Phone: 1 208 239 1541
 Fax: 1 208 232 7411
 Email: xuxm@isu.edu

#AADE19

29

DOC for predicting prediabetes

- Infodemiology
- Study 20 people recently diagnosed with prediabetes
- Study Facebook postings 3 months before diagnosis to three months after diagnosis
- Create a taxonomy for social media indicators for prediabetes

#AADE19

30

**WHAT RESEARCH
METHODOLOGIES ARE USED?**

#AADE19

31

32

Original Article

Twitter Analysis of #OpenAPS DIY Artificial Pancreas Technology Use Suggests Improved A1C and Quality of Life

Michelle L. Litchman, PhD, FNP-BC, FAANP^{1,2},
Dana Lewis, BA¹, Lesly A. Kelly, PhD, RN⁴,
and Perry M. Gee, PhD, RN^{1,5}

Abstract
Background: Patient-driven innovation in diabetes management has resulted in a group of people with type 1 diabetes who choose to build and share knowledge around a do-it-yourself (DIY) open source artificial pancreas systems (OpenAPS). The purpose of this study was to 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.

Journal of Diabetes Science and Technology
1-2
© 2018 Diabetes Technology Society
Article reuse guidelines:
sagepub.com/journalsPermissions
DOI: 10.1177/1932294818795705
journals.sagepub.com/home/dx
SAGE

33

Twitter analysis

- Qualitative Netnography
- 328 people with diabetes, caregivers, care partners
- 3347 tweets
- OpenAPS changes lives
 - OpenAPS users self reported decreases in A1C and glucose
 - OpenAPS improves sense of diabetes burden and QOL
 - OpenAps perceived as safe
 - OpenAPS - patient/provider relationships
 - OpenAPS technology adapted for users needs

#AADE19

34



#AADE19

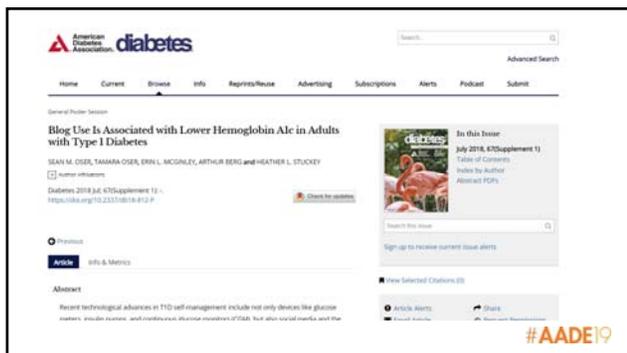
35

Exploratory mixed-methods study

- Examined Instagram photos with the #Dexcom over a 3-month period
- 2923 photos were screened for CMG location (determined location for 353 of the images)
- Analyzed comments as well
- 225 or 63% were worn in an off label location
- 23% were in an FDA approved location (e.g., abdomen)

#AADE19

36



40

Survey

- 282 completed surveys
- A1c was lower for blog readers than blog non-readers (7. vs. 7.48, P=.006)
- for insulin pump users than multiple daily injections (7.04 vs. 7.65, P=.001), and
- for CGM users than CGM non-users (6.99 vs. 7.47, P=.001).
- After adjusting for significant covariates, the association between blog use and A1c remained significant (P=.039).

S. Oser et al, 29018

41

DIABETES Oser et al

Original Paper

A Novel Approach to Identifying Barriers and Facilitators in Raising a Child With Type 1 Diabetes: Qualitative Analysis of Caregiver Blogs

—

Sarah M Oser¹, MD, Sarah M Oser², MD, MPH, Erin L McGinley¹, BS, Heather L Stuckey¹, DEd

¹Department of Family and Community Medicine, Penn State College of Medicine, Hershey, PA, United States
²Department of Internal Medicine, Biostatistics, and Public Health Sciences, Penn State College of Medicine, Hershey, PA, United States

Corresponding Author:
 Sarah M Oser, MD
 Department of Family and Community Medicine
 Penn State College of Medicine
 500 University Drive, H0-514
 Hershey, PA, 17033
 United States
 Phone: 717 531 8347
 Fax: 717 531 9524
 Email: osers@psmed.psu.edu

Abstract

Background: With rising incidence of type 1 diabetes (T1D) diagnosis among children and the high levels of distress experienced by the caregivers of these children, caregiver support is becoming increasingly important. Historically, relatively few support resources have existed. Increasing use of the Internet, and blogs in particular, has seen a growth of peer support between caregivers of children with T1D.

42

Qualitative analysis

- Five major themes emerged: (1) the impact of the child's diagnosis, (2) the burden of intense self-management
- experienced in caring for a child with T1D, (3) caregivers' use of technology to ease their fear of hypoglycemia and impacts that
- device alarms associated with this technology have on caregiver burden, (4) caregivers' perceptions of frequently missed or
- delayed diagnosis of T1D and the frustration this causes, and (5) the resilience that caregivers develop despite the burdens they
- experience. Misinformation was exceedingly rare and benign when it did occur.

(T. Oser et al, 2018)



43

Motivations for Participation in an Online Social Media Community for Diabetes

Journal of Diabetes Science and Technology
 2018, Vol. 12(3) 712-718
 © 2018 Diabetes Technology Society
 Reprints and permissions:
sagepub.com/journalsPermissions.nav
 DOI: 10.1177/1932296817749611
journals.sagepub.com/home/dts

Katherine White, BS¹, Achameleh Gebremariam, MS¹,
 Dana Lewis, BA², Weston Nordgren¹, James Wedding, BS, PE^{1,4},
 Josh Pasek, PhD⁴, Ashley Garrity, MPH^{1,5}, Emily Hirschfeld, BA¹,
 and Joyce M. Lee, MD, MPH^{1,5}

Abstract

Background: Our objectives were to describe individuals' 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.

Methods: A purposive survey was delivered to participants recruited through posts on the CGM in the Cloud group, Twitter, and blogs. Individuals were asked a series of demographic and social media use questions.

Results: A total of 1268 members of the CGM in the Cloud community responded to the survey. The majority were non-Hispanic White (92.1%) and caregivers of an individual with diabetes (80.9%). Mean age was 41 years old, and 74.8% were female.

44

Survey of Facebook group

- A total of 1268 members of the CGM in the Cloud community responded to the survey.
- The majority were non-Hispanic White (92.1%) and caregivers of an individual with diabetes (80.9%). Mean age was 41 years old, and 74.8% were female.
- Primary goals of the Facebook group were to learn more about Nightscout technology and to receive technological assistance.
- Respondents put a high level of trust in their peers versus health professionals in many health situations with nearly
- 40% of individuals reported to be helped by following advice found in the Facebook group, and 99% reported no harm.

(White et al., 2018)



45

DEVELOPMENT OF A DOC RESEARCH COUNCIL

#AADE19

46

Symposium/Special Issue

Development of the Intercultural Diabetes Online Community Research Council: Codesign and Social Media Processes

Journal of Diabetes Science and Technology
2:11
© 2018 Diabetes Technology Society
Check for updates
DOI: 10.1177/1932296518819444
jds.sagepub.com/home/jds
@SAGE

Deborah A. Greenwood, PhD, RN, BC-ADM, CDE, FADE¹,
Michelle L. Litchman, PhD, FNP-BC, CDE, FAANP²,
Ashley H. Ng, PhD, APD³, Perry M. Gee, PhD, RN⁴,
Heather M. Young, PhD, RN, FAAN⁵, Mila Ferrer, BA⁶,
Jimmy Ferrer, BA⁶, Chris E. Memering, BSN, RN, CDE, FADE³,
Barbara Eichorst, MS, RD, CDE⁷, Renza Scibilla¹⁰,
and Lisa M. S. Miller, PhD¹¹

Abstract
Background: This case study describes the formation of the Intercultural Diabetes Online Community Research Council (IDOCr) and community advisory board (CAB) to engage the diabetes community and researchers in the codesign of community-based participatory research (CBPR) to examine online peer support in type 2 diabetes (T2D).
Methods: Social media engagement was the foundation for CBPR knowledge generation. During the project, the IDOCr council and CAB (n = 27) met quarterly via video conferencing and three times in person during national diabetes meetings. Data from four Twitter chats were used to explore the usefulness and utility of Twitter data to learn about concerns and priorities of the diabetes online community (DOC) and supported the evolution of IDOCr, the development of a research question and the design of a CBPR study.
Results: The IDOCr project (1) created a diverse CAB; (2) raised awareness of IDOCr and online peer support, which

47

SCOPING REVIEW OF DOC RESEARCH

#AADE19

48



49

Scoping Review AIMS

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

(Litchman et al., 2019)

50

Methods used

- Scoping review of papers prior to 2018
- Evaluated a total of 14,486 and the team identified 47 that met inclusion criteria
- The 47 papers were carefully evaluated by the research team

(Litchman et al., 2019)

51

Health Outcomes Related to DOC Use

- DOC use was associated with neutral or lower A1C
- Psychosocial health is positively associated with DOC use by way of shared experience, social support and empowerment
- DOC users are reporting behavior change related to peer support by increasing self-care activities, and feeling motivated and accountable
- DOC users want healthcare providers, such as diabetes educators, to be aware of DOCs and to enhance their understanding of diabetes and the value of the community
- HCPs are not always supportive of DOC use, though when they are, people with diabetes are more likely to use DOCs
- Overall, the DOC is helpful most of the time with very little harm reported

(Litchman et al., 2019)

#AADE19

52

DOC participation concerns

- Misinformation in DOCs is uncommon, occurring 0-9% of the time.
- Though DOCs are being used to gain information about risky behaviors and ask about acute concerns – may fear lecture from provider
- Infighting between people living with type 1 diabetes and type 2 diabetes is sometimes present and likely rooted in misconceptions and stigma.
- Parents of children with diabetes may struggle more in comparison to other DOC users.
- Privacy in the context of health information sharing online varied.

(Litchman et al., 2019)

#AADE19

53



54

Questions?

-  Perry.Gee@imail.org
-  @gee_perry
-  Perry Gee
-  Perry M. Gee



#AADE19
