Disclosure to Participants

• Notice of Requirements For Successful Completion
  - Please refer to learning goals and objectives
  - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours
• Conflict of Interest (COI) and Financial Relationship Disclosures:
  - None
• Non-Endorsement of Products
  - None
• Off-Label Use:
  - None
WILL PEOPLE WITH DIABETES HAVE ACCESS TO THE DOC?

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.
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.


WHAT IS AADE'S HISTORY WITH DOC RESEARCH?

\[\text{#AADE}\]

"Patient Engagement is the Blockbuster Drug of the Century"

\[\text{Greenwood & Gee, 2013}\]
Exploration of the e-patient phenomenon in nursing informatics

(Parry & Co, 2013)

DIKW Collaboration Model

(Parry & Co, 2013)

Research

- Patients made more informed treatment decisions, managed symptoms more effectively, and monitored effects of treatments by participating in online communities.
- 123 participants (19%)
- 12% changed providers
- 41% of HIV patients reduced risky behaviors
- 22% of mood disorder patients needed less inpatient care

(Parry & Co, 2013)
Online Survey of DOC Users

- Demographics
- Health History
- Web 2.0 Application Use
- Help Health
- DOC Benefits
- DOC Intensity Scale
- DOC Engagement
- Internet Social Capital Scale

(Litchman, 2015)

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

(Litchman, 2015)

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

(Litchman, 2015)
IS THE DOC ONLY FOR MILLENNIALS?

Perceptions of Diabetes Online Community Credibility, Social Capital, Help and Harm: Cross-Section Analysis of Baby Boomers and Younger Adults

- Michelle L. Litchman and Linda S. Edelman 2019 (University of Utah)
- How do the perceptions of older adults who participate in the DOC differ than younger adults?
- Sample size of 76 baby boomers and 102 younger adults (most were Type 1, white, insured, educated, and female)
- Baby boomers and younger adults perceived the DOC credibility, social capital, help and harm similarly
- Both groups found the DOC credible but found their health care providers to be even more credible and trustworthy
- ~70% found the DOC helpful and <2% perceived harm
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

Can studying the DOC help us predict health issues?
Tu Diabetes
- Patient Engagement
  - 24.2% responded
  - 99.5% future
  - research context
  - 33.7% posted A1C
  - on profile page

(Greenwood & Gee, 2013)

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
WHAT RESEARCH METHODOLOGIES ARE USED?

#AADE19

#WeAreNotWaiting: “I Want Life”
The Medical Device Hacking Patient Movement

Meet the Team

Abstract

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

Michelle L. Litchman, PhD, FNP-BC, FAANP1,2
Dana Lewis, BA3, Lesly A. Kelly, PhD, RN1
and Perry M. Getz, PhD, RN1

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 system (#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.

The study analyzed 13,067 tweets and found that #OpenAPS was perceived positively by patients, caregivers, and care partners. It was viewed as a tool that improved quality of life and overall diabetes management.
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

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)
Survey of DOC users

- 183 adults from 4 different DOCs
- A1C, QOL, self care inventory, DOC use
- Mostly white females, with type 1
- Better QOL, better self care, lower A1C
- 67% did not tell their providers they were part of the DOC

(Litchman, Edelman & Donaldson, 2017)
Survey

- 282 completed surveys
- A1c was lower for blog readers than blog non-readers (7.3 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).

5. Oser et al, 2018
Qualitative analysis

- Five major themes emerged: (1) the impact of the child’s diagnosis, (2) the burden of intense self-management, (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)

Motivations for Participation in an Online Social Media Community for Diabetes

Katherine White, BS, Achamyeleh Gobremariam, MS, Dana Lewis, BA, Weston Nordgren, James Wedell, BS, PE, Josh Pauck, PhD, Ashley Garrett, MPH, Emily Hirschfeld, BA, and Joyce M. Lee, MD, MPH

Abstract

Background: Our objectives were to describe the 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.

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)
DEVELOPMENT OF A DOC RESEARCH COUNCIL

SCOPING REVIEW OF DOC RESEARCH
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)

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)
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)

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)

In summary, the DOC is a good thing and more research is needed.