Use of Social Media and Peer Support in Diabetes Care: A Panel from AADE Project Leaders

Deborah Greenwood, PhD, RN, BC-ADM, CDE, FAADe – President, Deborah Greenwood Consulting
Ashley Ng, PhD, APD, RD – Lecturer, Diabetes and Human Nutrition, La Trobe University
Michelle Litchman, PhD, FNP-BC, FAANP – Assistant Professor / Nurse Practitioner, University of Utah College of Nursing
Hope Warshaw, MMSc, RD, CDE, BC-ADM, FAADe – Owner, Hope Warshaw Associates, LLC

Disclosure to Participants

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  – 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

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- Conflict of Interest (COI) and Financial Relationship Disclosures:
  - Presenter: Deborah Greenwood, PhD., RN, CDE, BC-ADM, No COI to declare. Financial Relationships: Consultant: Mytonomy, Lifescan Diabetes Institute; Advisory Board: Novo Nordisk
  - Presenter: Ashley Ng, PhD, APD. No COI to declare. Financial Relationship: Consumer Consultant for Roche Diabetes Care, Australia
  - Presenter: Michelle Litchman. No disclosures to declare
  - Presenter: Hope Warshaw, Common Sensing. No COI to declare. Financial relationship: Consultant / Advisory Board: Heartland Food Group; Product / Consultant / Advisory Board: Lifescan; Consultant / Advisory Board: Welldoc; Consultant / Advisory Board: Mytonomy

Deborah Greenwood
PHD, RN, BC-ADM, CDE, FAADE
President,
Deborah Greenwood Consulting
Adjunct Assistant Professor,
Arizona State University

Objectives

- Identify the concept of co-design when using social media for research
- Discuss the results of a scoping review of online peer support
- Discuss the implications of online peer support for diabetes educators
Special Section on Diabetes and Social Media
Journal of Diabetes Science and Technology
March & May 2019

Engage in the Conversation!
@DebGreenwood
@HangryPancreas
@MichLitch
@HopeWarshaw

Annual time spent healthcare setting: 5 hours or 0.1% of year
Annual time spent on one's own: 5,000 waking hours or 99.9% of year
What are PWD Doing Online?

What are HCPs Doing Online?

Facebook for Support
“The most exciting innovation is not just access to information, but access to each other.”

Susanna Fox
Former Chief Technology Officer
Huffington Post 2015
Identifying the Problem

- Lack of co-design research to support online peer support diabetes communities
- Patient-Centered Outcomes Research Institute (PCORI) Pipeline to Proposal award
  - Three year award
  - Focuses on building partnerships with various key stakeholders within a specific health issue
  - Aims to develop a patient-centered outcomes research proposal

iDOCr - The Three Tiers
iDOCr - A Collective Goal

- To partner with people affected by diabetes to identify research priority areas to improve health outcomes aka Community-Based Participatory Research (CBPR)
- Who are our key stakeholders?
  - People with T1D and T2D, caregivers, healthcare providers, researchers, representatives from industry and advocacy groups
  - Resulted in a diverse Community Advisory Board (CAB)
- CAB met quarterly via Google Hangout + 3x in-person at national diabetes meetings (ADA + AADE)

iDOCr - Community Advisory Board

| Table 1: Shows Community Advisory Board Membership for Tier I
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<tr>
<td>#</td>
<td>Name</td>
<td>Organization</td>
<td>Position</td>
<td>Gender</td>
<td>Race</td>
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<tr>
<td>1</td>
<td>John Doe</td>
<td>American Diabetes Association</td>
<td>Executive Director</td>
<td>Male</td>
<td>White</td>
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<tr>
<td>2</td>
<td>Jane Smith</td>
<td>American Association of Diabetes Educators</td>
<td>President</td>
<td>Female</td>
<td>Hispanic</td>
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iDOCr - Informing the Research

- Exploratory research using Tweetchats
  - Learning the concerns and priorities from the diabetes online community
- 2015: #WDDChat15 and #iDOCD
  - Health outcomes DOC users perceived could improve through participation in the DOC and how individuals with T2D could be encouraged to participate
  - 781 Tweets from 85 individuals analysed
- 2016: #WDDChat16 and #iDOCD
  - Exploring stigma in diabetes to expand upon Tier I findings
  - 1107 Tweets from 150 individuals analysed
iDOCr - Tweetchat Findings

<table>
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<tr>
<th>[2015] #WDDChat15 + #DCDE</th>
<th>[2016] #WDDChat16 + #DCDE</th>
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<td>Improved social connectedness</td>
<td>Judgement around diabetes from others including health care providers</td>
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<td>Enhanced sense of wellbeing</td>
<td>PWD feel compelled to educate others about the condition</td>
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<td>Empowerment of self-management skills</td>
<td>Productive patient-provider teams are important</td>
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<td>Overcoming stigma</td>
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<td>Encouraging health care provider engagement</td>
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<td>Managing barriers</td>
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iDOCr - The Research Questions

- People with type 2 diabetes
- Hispanic/Spanish speaking population
- Diabetes Technology
- Online peer support

iDOCr - Where to now?

- Leadership team: Deborah Greenwood, Michelle Litchman, Ashley Ng
- Abbott Diabetes Care Grant
  - Combining Flash Glucose Monitoring and Online Peer Support to Improve Outcomes in Hispanic Spanish-Speaking People with Type 2 Diabetes: A Mixed Methods, pre-post design
- Keep up with our research:
  - Website: www.idocruncil.com/
  - Facebook: www.facebook.com/idocr/
  - Twitter: https://twitter.com/IDocr
Goal

Understand the benefits and negative consequences associated with DOC use

Scoping Review
Scoping Review

Understand the benefits and negative consequences associated with DOC use

14,483 Articles Screened
Ovid/MEDLINE | EMBASE | CINAHL | PsychINFO
Web of Science | EBSCOhost

47 Studies
Scoping Review

Research Question
Identify Relevant Studies
Select Studies
Chart the Data
Synthesize

Users Studied
- 92 countries
- Age 12-82
- T1D
- Females>Males
- White
- Educated

Platforms

Benefits
A1C Benefits

- <7%
- Neutral
- ≥7%
  
  Adults*
  Pediatrics
  Teens

* DOC Use

Psychosocial Benefits

- Shared Experience
- Social Support
- Empowerment

Behavioral Benefits

- Motivation
- Accountability
- Self-Care
Community Building

- Linguistic solidarity
- Multiple platforms
- Altruism

Negative Consequences

Help or Harm

- Helpful 38-70% of the time
- Harmful 0.07-1.8% of the time
**Information Quality**
- Potentially misleading information 0-9% of the time.

**Risky Behavior**
- Alcohol or drug use
- Diabulemia
- Acute issues

**Psychosocial**
- Emotional or Hostile Conflict
- Parents
Privacy
- Private group vs public
- “friends” vs strangers
- Lurking

Inactivity
- Lack of data

Gaps
- Lack of DOC definition
- Description of DOC users/platforms
- Multiple DOC platforms
- Methods
- Privacy
Conclusion

- Most research focused on singular platform
- Lack of diversity
- Beneficial with little harm noted

Hope Warshaw
MMSc, RD, CDE, BC-ADM, FAADE
Owner, Hope Warshaw Associates, LLC
Asheville NC

Define Ongoing Diabetes Support

"...resources that help the participant implement and sustain the ongoing skills, knowledge, and behavior changes needed to manage their condition."1,2,3

Literature Supports Value of Peer Support

Demonstrates potential to improve outcomes\(^1,2\)
- Clinical
- Self-management behaviors
- Psychosocial outcomes/quality of life
- Community

\(^2\) Litchman ML, et al. Online and in-person peer support in diabetes care: a review of reviews and practice recommendations. (in development)

AADE 2016-2018 Strategic Plan

The AADE7
AADE and PSC ~2010 – 2017:
Informal and Individual

- Annual conference presentations about DOC, social networking/media, value of peer support
- Increasing number of panels at annual conference with PSC members
- Host a DSMA Live Twitter Chat (2016 – 2018)
- Engage with several PSC on projects that support each other’s missions

Building Bridges Between AADE and PSC

Covers:
- Addressing positive mental outlook, minimization of psychosocial barriers increasingly important.
- Availability/accessibility of social media and networking has increased exponentially, will continue.
- AADE desire to more formally work with diabetes PSC and leaders.
- Details meeting goals, principles, outcomes, and near future actions.

AADE and PSC: 10/2017

- Meeting preparation
- Hire facilitator
- ~25 people in attendance
  - AADE leaders and engaged members
  - PSC leaders and members
  - AADE staff
AADE and PSC: 10/2017

Goals:1,2

• ID concrete ways for AADE/diabetes educators and PSC to work together more effectively and in tandem.
• Cross-promote the value of ongoing peer support and DSMES delivered by diabetes educators with recognition that both services are currently underutilized.
• Recognition that ongoing collaboration between the two previously silo-ed entities had potential to lead to new and innovative avenues to support each other’s goals.


AADE and PSC: 10/2017

Consensus meeting outputs:

• Mutually agreed to goals and efforts
• Set of shared principles
• Honest discussion of barriers (aired dirty laundry)
• Developed actions to address barriers
• Formal set of actions for AADE and PSC


AADE and PSC – Major Actions 2018

Actions post 10/17 meeting

• AADE18 – In-person gathering to recap progress, discuss future opportunities for the collaboration
• Initiate Peer Support section of AADE website1
• Financial support Litchman et al scoping review (JDST)
• Publication on AADE-PSC collaboration (JDST)
• Add peer support info to AADE’s Core Concepts course
• Programs at AADE18 on peer support, importance of mental health
• …more

AADE and PSC – Major Actions 2019

- AADE BOD appoints workgroup under SMRC and develops charges
- AADE19 – In-person gathering to recap progress, discuss future opportunities for the collaboration
- Writing group/publications:
  - Systematic review of reviews on peer support
  - Defining the Domain of Support and the Role of the DE/S in Delivering Support/Promoting Peer Support as part of DSMES
- Survey of DSMES DEAP programs on ongoing support and peer support

Survey Results DSMES DEAP programs on ongoing support and peer support

- (Will need to add in future)

Encourage Engagement with PSC

- Review, use AADE resources (Learn – Connect – Engage)
- Promote peer support for PWD, caregivers
  - Inquire about interest
  - Refer to specific communities based on needs
  - Follow up, ask about engagement
- Invite members of PSC to speak in class, at programs, LNG, CB (AADE staff can be conduit)
- Engage with PSC members at meetings, online (lurk ‘n learn)
- Opportunities to gain greater sensitivity, build relationships, raise awareness and importance of value of diabetes educators/DSMES
Building Bridges Leads to Improved Diabetes Care and Outcomes

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