Dual Training in Diabetes and Geriatrics Needed: Diabetes Online Community User Perceptions of Successful Aging

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ABSTRACT

Background
According to the American Diabetes Association there are approximately 30.3 million Americans with Diabetes, and the incidence is growing by nearly 1.5 million cases per year. These individuals are at particularly high risk of developing secondary comorbid conditions related to diabetes and aging. Nearly 45% of individuals 65-75 years of age state using social media, and this number is steadily growing. The use of social media provides the opportunity to assess the perceptions and needs of this population.

Objective
The purpose of this study was to examine stakeholder perceptions of aging with diabetes.

Methods
This study presents a retrospective analysis of a tweet chat focused on aging with diabetes. Tweets were collected using Symplur Signals and analyzed for content analysis, sentiment, and participant demographics. Two authors reviewed discussion posts for accuracy of analysis.

Results
A total of 59 individuals participated in this tweet chat, generating 494 tweets, and nearly 2 million impressions. Most (61.5%) of tweet chat participants were patients while 23% were caregivers and advocates. Seven countries were represented in the conversation. A majority (71%) of the tweets indicated positive sentiment related to aging with diabetes. Five major themes emerged from the qualitative analysis: 1) concern about personal decline now and in the future, 2) worry about limited access to treatment, 3) uneasy about inability to provide self-care, 4) healthcare provider capacity to support aging with diabetes and 5) interest in life-long online peer support to facilitate diabetes management.

Conclusions
Individuals with diabetes are living longer and want to be supported by specialized care and access to technology that will allow them to successfully age. Normal changes related to aging and diabetes-related complications may complicate diabetes management into old age. Stakeholders desire options to age in place, therefore, special training for care partners and healthcare providers who care for older adults is needed.

Keywords: Diabetes, Aging, Social Media, Twitter
Introduction

According to the American Diabetes Association there are approximately 30.3 million Americans with Diabetes, and the incidence is growing by nearly 1.5 million cases per year [1]. Further, the population of older adults aged 65 years old and older is growing [2], incidence of diabetes among this older population is over 25% [1]. By 2050, the number of adults in the United States aged 65 or older will nearly double to about 83.7 million [3]. Individuals with diabetes are now living 15 years longer than those diagnosed in 1950-1960 [4]. Despite the increased needs of the population, there is a lack of research focused on successful aging among individuals living with diabetes.

The normal aging process and diabetes can both contribute to functional impairment or disability. Self-management, independence, and quality of life can be negatively impacted when functional impairments or disability are present [5, 6]. Impairments may include sensory limitations, such as hearing, vision or touch; or may include biomechanical limitations, including immobility, weakness or tremors [7-9]. In addition to sensory and biomechanical impairments, cognitive decline associated with the aging process or diabetes may complicate self-management, increasing risk the for hospitalization and hypoglycemia [10, 11].

It is important to understand the perception of aging in those living with diabetes. Yet, there is a gap in the literature regarding how individuals currently living with diabetes view the future. Nearly 45% of individuals 65-75 years state using social media, and this number is steadily growing [12]. Social media has made it possible for individuals with diabetes to engage in peer health, defined as the interaction, education, and support offered by peers with the same condition to promote self-care [13, 14]. One way that individuals engage in diabetes-related conversations is through tweet chats on Twitter. Tweet chats are scheduled discussions that use a pre-identified hashtag. #DSMA (Diabetes Social Media Advocacy), is a weekly tweet chat for individuals affected by diabetes and has been in place since July 2010. #DSMA tweet chat topics vary from week to week and participant stakeholders include patients, care partners, health care providers and advocacy organizations. Analyzing discussions on social media, such as the #DSMA tweet chat, provides an opportunity for researchers and clinicians to understand perceptions on topics such as aging from various diabetes stakeholders. The purpose of this study was to determine stakeholder perceptions of aging with diabetes.

Methods

Sampling

A retrospective analysis of the #DSMA tweet chat focused on diabetes and aging that occurred on April 13, 2016 was undertaken. Approval from the University of Utah Institutional Review Board (IRB) was sought but deemed unnecessary given the public availability of tweets. The tweet chat consisted of 5 questions (see Table 1), and closing thoughts, which were posed by the #DSMA moderator.

<table>
<thead>
<tr>
<th>Table 1. DSMA Questions</th>
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<tbody>
<tr>
<td>Q1. How do you define successful aging with diabetes? #dsma</td>
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<td>Q2. What are your concerns about aging with diabetes? #dsma</td>
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<tr>
<td>Q3. How can healthcare providers help or hinder successful aging? #dsma</td>
</tr>
<tr>
<td>Q4. How can technology help or hinder successful aging? #dsma</td>
</tr>
<tr>
<td>Q5. How can the DOC support you and your diabetes as you age? #dsma</td>
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Symplur Signals (Los Angeles, California) was used to extract data during the 60-minute tweet chat, and 15 minutes following the chat to capture any continued conversation that may have occurred. Symplur Signals is an analytics platform that is directly linked to the Twitter application program interface and has the capability to assign healthcare stakeholder designation (i.e., patient, caregiver, physician, other healthcare provider, industry, etc.) based on Twitter account biographies [15]. In addition, language used in tweets and geographic location of the participant data can be collected to further analyze demographic information.

**Analysis**

Various tools from Symplur Signals [15] were employed to extract healthcare stakeholder designation. Accuracy was determined by one of the authors (CS) by initially reviewing the healthcare stakeholder designation populated by Symplur Signals and making adjustments as needed to correct the information (i.e. changing caregiver/advocate to patient). The healthcare stakeholder designation was then reviewed by a second author (ML) to determine credibility.

Symplur Signals [15] assigns numbers to each word in the tweet as it relates to sentiment. Scores are based on the degree of negativity (-6 through -1), positivity (1-6) and neutrality (0). Scores were reviewed by two independent reviewers (MLL and PMG) and adjusted as needed to address unique words and phrases that may have positive meaning but given a negative score and vice versa. A word cloud was developed to identify the most common words used in the tweet chat.

A content analysis of retrospective Twitter transcripts was conducted. The tweet chat script was downloaded and de-identified to protect identity. Tweet data were cleaned and Question responses from Table 1 were grouped. Data were read, line by line, by two independent investigators. Two independent researchers coded data (MLL and PMG) using an open code approach while a third author (CS) facilitated consensus to establish credibility. Themes were then developed from the codes [16]. The frequency of codes, uniquely identified in social media research as retweets, were used to assess the content of the data but not to determine data saturation [17]. Quotes used in the results below were slightly altered, while maintaining the meaning of the tweet, in order to protect identity.

**Results**

There were 59 total participants who generated 494 tweets, 104 retweets, 110 replies, 220 mentions, 5 tweets with links, 2 tweets with photos and 1,966,945 impressions in the tweet chat. The conversation was dominated by patients (61.5%) and caregivers/advocates (23.1%), see Figure 1. The tweet chat was global in nature, including individuals from 7 known countries (United States of America (N=31), Canada (N=3), Italy (N=2), Sudan (N=1), Phillipines (N=1), Peru (N=1), Australia (N=1). There were participants from 19 unknown countries. The top 25 words used in during the tweet chat are noted in Figure 2. Sentiment analysis was overwhelmingly positive (71% of tweets) and were similar in positivity between patients (71%) and advocates/caregivers (77%), see Figure 3.
The qualitative analysis provided unique insight into how individuals with diabetes view aging. The analysis resulted in five major themes, discussed below: 1) concern about personal decline now and in the future, 2) worry about limited access to treatment, 3) uneasy about inability to provide self-care, 4) healthcare provider capacity to support aging with diabetes and 5) interest in life-long online peer support to facilitate diabetes management.

**Concern about Personal Decline Now and in the Future**

Participants overwhelmingly felt that successful aging was the process of getting older without feeling sicker. Feeling sicker was directed towards having diabetes-related complications or feeling more tired or older than chronologically similar peers without diabetes. Some participants felt that diabetes-related complications might be inevitable, while others were already experiencing diabetes-related complications. One participant noted, “That no complications ship has sailed, my friend. And I’m still aging, still here, still fighting the good fight.” In general, the act of aging at all with diabetes was viewed positively. One participant noted, “Aging with diabetes is automatically a success, living without complications is a bonus. Aging at all beats the alternative.”

Individuals were optimistic about the idea of living into old age, noting that they would do the best they could in order to age successfully. Tactics to achieve this included staying positive and addressing challenges as they came. While some participants were looking forward to aging in the future, some participants noted that they had already aged successfully. One participant noted, “Successfully aging is getting a Joslin 50-year medal and still appreciating the fact that you’re alive and can still laugh.”

**Worry about Limited Access to Treatment**

Participants wanted to access similar treatments, including technology, that they are accustomed to now. Participants expressed worry about access to affordable care as they aged. Access related to both insurance coverage and affordability. Specifically, participants were concerned with access to medications (with an emphasis on insulin), medical supplies (i.e., glucose test strips), medical devices (i.e., insulin pump, continuous glucose monitor), and lab
work. One individual noted, “The way things are going, insulin will eventually cost a zillion dollars a year.”

Participants identified the current coverage for older adults (i.e., Medicare) specific to technology as undesirable and unable to meet their diabetes management needs. One participant noted, “If people have access to tech and then they can't afford it anymore or it's not covered, it's a problem.” Addressing barriers to access were viewed as important in being able to successfully manage diabetes into old age.

Uneasy about Inability to Provide Self-Care and Need for Care Partners

Participants expressed positive sentiment about using technology that may help them if they should experience usual changes in aging, such as hearing, vision and cognitive changes (ie, insulin pens that indicate the time of the last injection to support forgetfulness) but were concerned that they may lose the ability to continue their current treatment due to these age-related changes. These concerns were focused on inability to visualizing the screens on glucometers or insulin pumps, pushing buttons on insulin pumps, and drawing up and injecting insulin.

Loss of independence in diabetes management raised concerns. Participants wanted to be able to continue to provide self-care but were aware of normal age-related that may limit them. These limitations included changes in vision, strength, and cognitive function. As such, some participants worried about their future inability to address the physical and cognitive tasks related to managing their diabetes. These tasks included checking glucose, administering insulin, and making proper decisions about insulin dosing.

Changes in independence raised concern about burdening or becoming reliant on others for diabetes self-care. Some participants worried that they didn’t feel that they could trust another person to care for their diabetes at the same caliber as they were doing for themselves. One individual overtly stated that they were fearful of the diabetes care they would receive in a long-term care facility.

Healthcare Provider Capacity to Support Aging with Diabetes

Participants desired healthcare providers with dual expertise in aging and diabetes. There was concern that some providers wouldn’t have the knowledge to distinguish the difference between diabetes related complications and normal functions of aging. Further, participants noted that the diabetes duration in type 1 diabetes is often much longer in someone with type 1 diabetes compared to type 2 diabetes. One participant noted, “In my experience, few doctors know how to treat type 1 diabetes, especially those who have lived with the disease for decades.” Those who had diabetes for decades felt that there were things they could teach healthcare providers about longevity with diabetes.

Concern was expressed over how individuals are being approached by health care providers now, and how this would impact successful aging. The importance of receiving good care from healthcare providers today, while patients were younger, was viewed as important in aging with diabetes. Participants desire care that is tailored to their unique needs including diabetes type. One participant said, “[HCPs] are not geared to see how individuals needs vary, there is not a one size fits all treatment.” Other participants were discouraged by healthcare providers using negative approaches, such as scare tactics. Participants wanted their healthcare providers to
use positive approaches, enlisting hope in their ability to simultaneously manage their diabetes and age successfully.

**Interest in Life-Long Online Peer Support to Facilitate Diabetes Management**

Participants highly valued their relationship with others in the diabetes online community. There was consensus in participants wanting to continue their relationship with one another as they aged, “growing old together.” One participant noted, “The diabetes online community will always be there when I have ups and downs, highs and lows, good days and bad days.”

It was recognized that Twitter may not be available in the future. Participants noted that they would seek out other technology platforms. Some participants anticipated they may not be able to engage in technology as an older adult due to age-related changes, such as dexterity or vision issues. In these instances, participants planned to regress to handwritten letters in order maintain connected with their peers.

**Discussion**

This paper aimed to understand the perceptions of successful aging among diabetes stakeholders. The individuals who participated in the #DSMA tweet chat focused on successful aging gave unique perspectives of how they viewed successful aging, resulting in five emerging themes: 1) concern about personal decline now and in the future, 2) worry about limited access to treatment, 3) uneasy about inability to provide self-care, 4) healthcare provider capacity to support aging with diabetes and 5) interest in life-long online peer support to facilitate diabetes management. Below we discuss results and implications for the future.

Age-related decline coupled with diabetes related complications is concerning to individuals with diabetes. Importantly, these aging and diabetes related changes can impact the immediate family and care partners of people with diabetes. Recognizing the complex nature of the impact of diabetes can have not just on one person but on an entire family is crucial to improving diabetes treatment for people with diabetes transitioning from middle age to older adulthood.

Transitioning from middle age to older adulthood with diabetes is a life transition that is not well understood. Current guidelines suggest transition between adolescents and young adulthood requires additional education at least one year prior to transitioning to an adulthood [18]. During this developmental phase of life, individuals transitioning to young adulthood increase independence while the parent care partner(s) decrease support. While the aging process varies by individual, establishing transition education and processes may be helpful to support the transition from middle adulthood to older adulthood. Transition education needs in older adulthood include understanding the changes from commercial insurance to federally funded insurance, differentiating changes related to normal aging and diabetes complications, and how to navigate diabetes self-management if aging or diabetes complications were to occur. As older adults establish wills, power of attorneys, and other legal matters, individuals with diabetes may want to identify potential care partners (ie, spouses, children) that can become educated with self-management practices in order to better understand diabetes management needs should the person with diabetes become more dependent for care in the future.

Older adults are currently using diabetes related technology [19, 20] and this number will likely grow. Participants expressed desire in continuing the use of their insulin pumps and continuous glucose monitors into old age as long as they were able. Access to diabetes technology may be limited by insurance provider, resulting in some individuals who must change their current
diabetes management strategies. Normal age-related changes to vision, extremity function, and cognition may create challenges in continuing to use diabetes-related technology. Technology should support people with diabetes across all age groups and be designed to accommodate age-related changes, such as in vision, hearing and dexterity where possible.

Concerns were expressed that healthcare providers tailor care to meet their needs as they aged. Therefore, it is important that healthcare providers understand the aging process, how aging impacts diabetes, and how to best care for older adults with diabetes. In addition, individuals with diabetes are living longer [21]; however, their care and comorbidities may be very different depending on diabetes type and other health factors. There is an urgent need to increase the healthcare provider workforce with expertise in geriatrics/gerontology in order to meet the unique care needs of older adults with chronic conditions such as diabetes. The Institute of Medicine report, *Retooling for an Aging America: Building the Health Care Workforce*, reported that medical, nursing, pharmacy and other health care provider programs contained very little geriatric specific content [22]. At the time of the report, less than 1% of nurses and pharmacists were specialized in caring for older adults, and there was only 1 geriatrician for every 2,546 older adults [22]. With the older adult population increasing, and with a higher proportion of older adults living with diabetes, it is imperative that healthcare providers receive education about caring for older adults with chronic conditions, such as diabetes, and then seek specialized training in geriatrics.

The diabetes online community provides emotional support and knowledge [13, 23] and is associated with better glycemic levels, self-care, and quality of life [14]. We found that individuals planned to use technology and other means to remain connected to others within the diabetes online community. Loneliness in older adulthood can negatively impact health [24, 25] and addressing psychosocial needs is key to successful aging [26]. Having a larger support network, such as the DOC, may provide health benefits as individuals with diabetes age. Older adults who are limited by location or geography may still be able to use the internet to connect to online communities and engage with peers [27]. Older adults are adopting Internet usage at a pace faster than other groups and online social communities for older adults are steadily growing [27, 28]. Social support and connectedness may be the answer to promoting optimal self-management support for the older adult with diabetes. Caregivers of older adults in the future may need training to support patient social media or other technology use.

**Limitations**

Due to the nature of data collection on Twitter and Symplur Signals, we are unable to offer more precise demographic information, such as age, race and gender. However, tweets emphasized the desire for a healthcare provider workforce knowledgeable of type 1 diabetes, suggesting some of the individuals participating in the tweet chat analyzed were affected by type 1 diabetes in some way. More research is needed to understand aging needs of individuals with both type 1 and type 2 diabetes.

**Conclusions**

All individuals experience changes in health related to aging, however, those with diabetes may experience complications that might exacerbate these changes. In this study, diabetes healthcare stakeholders expressed a desire to prolong independence and age in place. Contrary to insurance coverage for some providers, individuals with diabetes need access to technology and medication coverage at the same or higher levels into older adulthood to facilitate positive diabetes management. In addition, dual training in geriatrics and diabetes
would increase healthcare provider ability to differentiate normal age-related changes and diabetes complications, thus providing specialized support to patients, which is currently limited. Finally, healthcare stakeholders expressed a desire for education to support care partners, and access to social support off- and online. Taking active steps towards the successful aging of individuals with diabetes will promote patient-centered care and may enhance health.

**Acknowledgements**
None.

**Conflicts of Interest**
None.

**Multimedia Appendix 1: [Med-X Presentation]**
References