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Abstract

Individuals with chronic disease search for health information online. The Diabetes Online Community (DOC) is an active community with members who exchange health information, yet very few studies have examined health information brokering in the DOC. The objective of this study was to develop and validate the Attitudes Toward Seeking Health Information (ATSOHI) scale in a sample of adults with type 1 diabetes (T1D). One hundred sixty-six people with T1D participated in this study. Confirmatory factor analyses determined a two-factor scale (Trusting and Evaluating Online Health Information in the DOC and Engaging with Online Health Information in the DOC) with good convergent validity and discriminant validity. Correlations were found between social support, online health information seeking, diabetes distress, and disease management. The ATSOHI scale can be used to investigate how people with diabetes are using the internet for health information and is especially relevant in the age of telehealth and health 2.0.

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Original Manuscript

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Abstract

Individuals with chronic disease search for health information online. The Diabetes Online

Community (DOC) is an active community with members who exchange health information, yet very few studies have examined health information brokering in the DOC. The objective of this study was to develop and validate the Attitudes Toward Seeking Health Information (ATSOHI) scale in a sample of adults with type 1 diabetes (T1D). One hundred sixty-six people with T1D participated in this study. Confirmatory factor analyses determined a two-factor scale (*Trusting and Evaluating Online Health Information in the DOC* and *Engaging with Online Health Information in the DOC*) with good convergent validity and discriminant validity. Correlations were found between social support, online health information seeking, diabetes distress, and disease management. The ATSOHI scale can be used to investigate how people with diabetes are using the internet for health information and is especially relevant in the age of telehealth and health 2.0.

INTRODUCTION

As health information is readily accessible online, there has been a shift in how individuals with chronic disease are acquiring health information (Fox and Duggan, 2013). People with type 1 diabetes (T1D) seek health information online from their peers and share anecdotal evidence and published articles (Hilliard et al., 2015). However, health practices that work extremely well for one person may be ineffective or even detrimental for another person.

People with T1D are also encouraged to engage in social support (CDC). Social support can

exert a positive effect on disease management and is key for psychological adjustment (Shelley et al., 2011), health information seeking (Greene et al., 2010), maintaining mental health (Turner and Brown, 2010) and physical health (Uchino 2004, 2009). In addition, for individuals with T1D, this social support is often experienced on social media platforms such as Facebook and Twitter (Oh & Cho 2015). More recently, the DOC has gained traction on Youtube (Abdoli et al., 2020), Instagram (Malik et al., 2021), and TikTok (Kong et al., 2021). There are many psychosocial benefits to participating in online chronic disease groups (Oser et al., 2020). Individuals with diabetes who participate in online support groups report increased empowerment (Van Uden-Kraan et al., 2008) as well as increased positive emotional experiences, increased positive attitudes towards T1D, and increased engagement in T1D management behaviors (Hilliard et al., 2015).

The current project sought to clarify several existing gaps in the literature due to the nature of existing health information-seeking measures not being tailored to those with chronic conditions. Various psychological assessment tools do not take into account if an individual has a chronic condition. The Krantz Health Opinion (Krantz, Baum and Wideman, 1980); the Miller Behavioral Style scale (Miller, 1987); Threatening Medical Situation (van Zuuren et al. 1996; Wakefield et al., 2007); and the Autonomy Preference Index (Ende, Kasiz, Moskowitz, 1989; Bonfils, 2015) are assessment tools that do not lend themselves to chronic conditions, as the measures propose a hypothetical medical condition and prompt responses based upon these hypothetical conditions. Few studies have been conducted in the DOC to collect data on online health information seeking (Litchman et al., 2019; Oser et al., 2020). The present study fills these gaps through the development and validation of a scale that measures seeking health information online for individuals with T1D and examining the relationships between key constructs.

METHODS

Mixed Methods Framework. This study employed mixed methods scale development (Onwuegbuzie et al., 2010) which uses feedback, and inductive and deductive information in a

strictly online setting. Items for the Attitudes Towards Seeking Online Health Information (ATSOHI) scale were developed in previous studies (Hughes et al., 2017; Hughes et al., 2019; Hughes et al., 2021). A qualitative pilot study found that participants were using online peer-to-peer provided health information to decide whether they would seek healthcare (Hughes et al., 2017). Based on the pilot study results and previous literature, a scale was developed. The next study focused on investigating the constructs and gaining feedback on the scale (Hughes et al., 2019; Hughes et al., 2021). Participants provided feedback on the wording of the items and for the present study, the scale features the edited items.

PARTICIPANTS

Participant eligibility required the following: 1) 18 years of age or older, 2) identifying as a member of the DOC and 3) having been diagnosed with T1D by a doctor. This study was approved by the Institutional Review Board at the University of Texas at El Paso. Participants were recruited from the DOC via Facebook posts, tweets using the hashtags #doc, #type1 diabetes and #dsma, and peer to peer referrals.

MEASURES

Participants accessed a link to the Qualtrics survey where they completed demographics, a health questionnaire, eHealth Literacy scale (eHEALS, Norman and Skinner, 2006), Social Provisions scale (Cutrona & Russell, 1987), Treatment Adherence scale (ARMS-D, Mayberry et al., 2013), and Diabetes Distress scale (Polonsky, 2005). Participants also provided qualitative feedback on clarity, esthetics, relevancy, tone, length of time needed to respond, and cultural competence of the ATSOHI scale. The scale is located in Table 1.

DATA ANALYSIS

Confirmatory factor analyses (CFA) were conducted using M*plus* 7.11 (Muthén & Muthén, 1998-2018). Robust maximum likelihood estimation was used in this model. The absolute fit indices included Satorra-Bentler scaled χ^2 statistic and Standardized Root Mean Square Residual (SRMR)

statistic. The relative fit indices included the Tucker-Lewis Index (TLI) and the Comparative Fit Index (CFI). Following factor analysis and model fit comparison guidelines (Hu and Bentler, 1999), CFA results were then compared to assess for model fit utilizing: SRMR < .09 in combination with either TLI or CFI < .96, or RMSEA > .06.

RESULTS

Descriptive statistics

One-hundred-seventy-five people with T1D participated in the study. Nine were excluded due to not meeting inclusion requirements. Of the 166 participants included in this sample, 89.8% identified as female with an average age of 34.33 years (11.249 years). The majority (89.8%) of sample participants were in the United States. Approximately 86.1% of participants were white. The average household income was $85,425.28 ($59,146.68, median = $74,500). Most participants (80%) reported obtaining additional education after high school. Average Hemoglobin A1c was 7.3% (1.36%) and more than half of the participants (53%) reported using an insulin pump. Of note, 81.9% take additional medications beyond insulin. For additional demographics and health demographics, see Table 2.

Qualitative Assessment of ATSOHI Scale

Participants provided many detailed responses from questions that should be added to the ATSOHI scale and overall general comments for improvement. [ID 110] "*The questions reflect an understanding of what t1s typically do in the online space. One question I would have liked to see, or at least something I'd add, is that my decision to follow advice in the DOC often depends on how well I feel I "know" the person giving the advice. (i.e, is he/she active in DOC, have I interacted with him/her in DOC, etc*)". Participants were also asked to address the cultural competency of the Attitudes Toward Seeking Health Information Online scale: [ID 129]: "*Each question was something someone living with type 1 diabetes could answer or relate to*." One participant identified how the

items correctly reflected what individuals with T1D experience [ID 179]: "*They understood the DOC is able to help through the disease, especially to avoid an appointment with the endo since those are hard to get sometimes*." Participants stated that the survey used participant-endorsed terminology and that questions seemed to indicate that the research team had knowledge of T1D, largely due to the level of detail.

Reliability of Measures

The reliability of the project's quantitative scales was assessed using coefficient α. Every scale exhibited good to excellent reliability (see Table 3 for more information).

Confirmatory Factor Analyses (CFA)

Following the suggestions of Brown (2015), a variety of plausible models were tested. A three-factor model and a two-factor CFA model, each with 16 items, were conducted.

The 3-factor model with 16 items

First, we conducted a 3-factor model CFA with 16 items (see Table 4 for factor loadings). Correlations between factors were: (Factor 1, Factor 2) = .942, (Factor 1, Factor 3) = .364, and (Factor 2, Factor 3) = .492. The high correlation between Factors 1 and 2 violated the discriminant validity of the measure. For this reason, Factor 3 was removed from the list of items and the next CFA was a 2-factor model. Items 13, 14, and 15 and 16 were moved to Factor 2 for the second CFA. Regarding model fit, the following indices did not demonstrate good model fit: Satorra-Bentler $\chi^2(101) = 271.026$, RMSEA = .101, 90% CI [.086, .115], CFI = .748, AIC = 8667.727 and SRMR = .086. Of note, there was a high correlation between Factors 1 and 2 (r = .997), but not between Factors 1 and 3 (r = .618) or Factors 2 and 3 (r = .591).

The 2-factor model with 16 items

Next, we tested a two-factor model with 16 items. Factor 1 is composed of items 1-7 and 8-12 and Factor 2 is composed of items 13-16 (see Table 5 for factor loadings). Regarding model fit, the following indices presented a good model fit: $\chi^2(103, N = 166) = 163.672$, RMSEA = .060, 90%

[.042, .076], CFI = .906, AIC = 8631.384 and SRMR = .072. In addition, the inter-factor correlation between factors 1 and 2 (r = .401).

Correlations (see correlations table for more information)

Importantly, several factors of diabetes distress were correlated with factors of the ATSOHI. Powerlessness and factor 1 (r = .198, p = .011), Hypoglycemia distress and factors 1 and 2 (r = .153, p = .049, r = .158, p = .042), Management distress and factor 2 (r = .169, p .029), Physician distress and factor 1 (r = .204, p = .008), and Family distress and factor 2: r = .219, p = .005.

Discussion

In this study, a scale examining online health information seeking for individuals with T1D was developed and validated. This scale measures multiple types of peer-provided social support and examines how peers broker health information. Scale development was necessary due to the lack of existing scales addressing real world experiences of chronic disease-related information seeking. We developed a reliable two-factor, 16 item scale. Furthermore, this project examined the relationships between the seeking health information online measure with eHealth literacy, social provisions, and diabetes distress to establish validity by demonstrating the magnitude of these relationships.

Regarding CFA model comparison, the two-factor 16 item scale had small, standardized residuals (Hu and Bentler, 1999) and provided good model fit. The majority of the project's scales had excellent reliability but a few scales used to validate the measure demonstrated adequate reliability, as indexed by coefficient alpha: Social Provisions-Social Integration, Social Provisions-Reassurance of Worth, Diabetes Distress-Management Distress, Diabetes Distress-Eating Distress, and Attitudes Towards Seeking Health Information Online (Factor 1), and fair for Attitudes Toward Seeking Health Information Online (Factor 2). Findings from this study will contribute to the knowledge base of the healthcare of adults with T1D. Participants were forthcoming about the items of the scale and providing recommendations, as they are a very active and communicative population in the context of social media.

As expected, both factors were positively related to eHealth literacy. Additionally, the Trusting and Evaluating Online Health Information factor was positively related to Social Provisions (Attachment, Social

Integration, Reassurance of Worth, Reliable Alliance, Guidance, and Opportunity). Thus, the present study extends what is known about informational support, as a type of social support to the context of online health information seeking. The Engaging with Online Health Information in the DOC factor was also found to be positively related to several types of Social Provisions (Attachment, Social Integration, Reassurance of Worth, Reliable Alliance, Guidance, and Opportunity for Nurturance). These relationships are to be expected, as informational support is a type of social support.

Diabetes Distress

Of interest, *Trusting and Evaluating Online Health Information* (factor 1) was positively related to multiple types of Diabetes Distress (Powerlessness, Hypoglycemia Distress, Physician Distress). These findings are a unique contribution to the T1D literature because they provide support that key diabetes-related constructs that impact health behaviors also impact health information seeking. These findings are significant because to the best of our knowledge, this study is the first to assess these relationships. These findings are a unique contribution to the T1D literature because they provide support that with more feelings of distress towards managing T1D, hypoglycemia-related distress, and diabetes-related distress related to friends and family, individuals are engaging more with online health information in the DOC. With more diabetes-related distress comes more engagement in the DOC and more trust in the information found online.

Limitations and Future Directions

Although this study provides an innovative, valid, and reliable scale, there are a few important limitations from which future research may build upon. The sample was mostly Caucasian, well-educated, and female. Future research in this area should also seek to collect data from minority populations because much of the existing DOC research does not represent the diversity that exists in the online community. Similar research considering and incorporating caregivers for adolescents with T1D would be beneficial because these individuals also engage in the DOC. The developed ATSOHI scale was created for the T1D community but could be tailored for other chronic disease groups who seek health information online.

Future research should be conducted based on the feedback provided in this study for the Attitudes Toward Seeking Health Information scale to further confirm the findings, further validate its factor structure, and establish reliability of those factors. Future research should aim to increase the reliability of both factors of the Attitudes Towards Seeking Health Information Online scale.

Conclusions

These findings provide support for the relationships between Attitudes Toward Seeking Health Information Online, Social Provisions, Diabetes Distress, and T1D related health outcomes and behaviors. With a better understanding of the roles of online social support and seeking health information online on disease management, this project serves as the first of several series of studies to improve usage of the DOC and facilitate constructions of interventions that encourage or discourage specific aspects of each behavior.

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