cogent
medicine

PUBLIC HEALTH & PRIMARY CARE | RESEARCH ARTICLE

Perceptions of telemedicine for patient education among online support group patients with chronic or rare conditions

Joan S Leafman[1]* and Kathleen Mathieson[1]

Abstract: Effective patient education among individuals with rare or chronic conditions is important for health outcomes, but difficult because of patients' evolving needs. Telemedicine for patient education (TPE) may facilitate communication between healthcare professionals and patients to improve health outcomes. This study aimed to explore potential benefits of TPE and to apply the Community of Inquiry (CoI) framework to examine perceptions of TPE among patients with rare or chronic conditions. Patients with rare or chronic conditions ($N = 274$) were recruited from an international online health community and completed a 46-item cross-sectional survey. The survey was based on previous research, underwent review by a panel of experts for face and content validity, and assessed patient perceptions of the CoI framework for TPE. Patients reported wide access to digital devices and high use of social media tools, particularly Facebook. While few patients had experienced TPE, most agreed that telemedicine was an excellent medium for patient education. Patients perceived all three elements of the CoI framework to be equally important for effective TPE. Results suggested that TPE meets a number of criteria perceived to be important for patients with rare and chronic conditions, and that the CoI is a viable TPE framework for this population.

ABOUT THE AUTHOR

Joan S Leafman, PhD and Kathleen Mathieson, PhD are associate professors in the Doctor of Health Sciences Program at A.T. Still University, College of Graduate Health Sciences. Both teach in the Applied Research Project (ARP) series of courses. Their current scholarship pursuits and publications are focused on the investigation and effects of social presence in online environments as well as telemedicine patient education as a means to improve outcomes for patients with rare or chronic conditions.

PUBLIC INTEREST STATEMENT

Do people from low and high socioeconomic status groups perceive problem situations differently? Perceptions of how the problems come about and of whether one is responsible for finding a solution may impact how individuals manage the problem. This study found that individuals who view themselves as being relatively well-off tend to feel more in control of their life in general, which in turn, relates to their focus on problem causes that are internal (i.e., individual characteristics), changeable and controllable, and see the self as responsible for dealing with their own problem. In contrast, those who view themselves as being less well-off tend to feel less control, which relates to their perceptions of problems as being externally caused, unchangeable, uncontrollable, and of themselves as less responsible for the problem solutions. The results provide further evidence for how people from different socioeconomic groups may perceive social experiences in different ways.

cogent·oa

Subjects: Communication Technology; Behaviour; Chronic Diseases

Keywords: telemedicine; patient education; digital communication

Disease management to optimize quality of life requires continuous engagement and coordination by the patient and a myriad of health professionals (Shipman, Lake, Van Der Volgen, & Doman, 2016). Chronic conditions lack an agreed upon "official" definition but always include health problems that are by nature limitless, persistent, and recurrent and have a duration measured minimally by months but usually years (Goodman, Posner, Huang, Parekh, & Koh, 2013). According to the Centers for Disease Control and Prevention and National Institutes of Health and based on the U.S. Rare Disease Act of 2002, rare medical conditions are defined as disorders that affect less than 200,000 people in the United States (GovTrack, 2002). For patients with rare or chronic conditions, support is often difficult to find and sustain. Further, diagnosis may be difficult, treatment may be challenging, medications can be perplexing, and health related patient education may be sparse; therefore, patients with rare or chronic conditions are often medically underserved (Goodman, Posner, Huang, Parekh, & Koh, 2013). Given that chronic health conditions are now the leading cause of death (Sav et al., 2015), it is imperative that efforts to better support these medically underserved patients be explored. Patient education is of particular interest because many rare and most chronic conditions persist over long periods and require patients to manage their own care (Shaha et al., 2015).

Patient education, as defined by the University of Texas Medical Branch is "an individualized, systematic, structured process to assess and impart knowledge or develop a skill in order to effect a change in behavior" (University of Texas Medical Branch, 2014, p.1).

Incorporation of patient education into a patient's care is key to successful self-management and improved health outcomes (Ross, Ohlsson, Blomberg, & Gustafsson, 2015). These outcomes include but are not limited to acquiring and implementing knowledge of treatment options; choosing medications and dosages; and incorporating behavior changes like diet, exercise, and stress reduction for optimum quality of life (Rodriguez de Bittner & Zaghab, 2011). For all patients, meaningful patient education is universally recognized as difficult (Jensen, Gabre, Skold, Birkhed, & Povlsen, 2014). Further, mode of education delivery, patient interest, and transfer of knowledge from theory to action present obstacles to successful results (Bombeke et al., 2012). Therefore, affecting change through patient education among patients with rare or chronic conditions is particularly difficult because of the sustained nature of the condition or disease as well as the continued and evolving needs of the patient (Tamura-Lis, 2013). It is even more challenging to provide access to effective patient education for those who are medically underserved (Jardins et al., 2015) because of added barriers related to lack of resources, geographic expanse and professional diagnosis, treatment, and forecast ambiguity (Torenholt et al., 2015).

One way to address the above barriers is to use telemedicine for patient education (TPE). Telemedicine technologies can facilitate communication between healthcare professionals and patients to address and improve health-related behaviors or health status. Further, TPE may be especially advantageous for patients with rare or chronic conditions. With over two-thirds of the U. S. population owning smart phones and reporting Internet access, TPE has proven to be cost efficient (Davis & Oakley-Girvan, 2015). In addition, telemedicine technologies are often available on demand and are geographically unrestricted, allowing for access anywhere and at any time (Stellefson et al., 2014). Further, patient education via digital technology can reach those who are nonambulatory (Banbury et al., 2014). TPE also allows for patient privacy, and patients with rare or chronic conditions consider privacy especially important (Seo, Goodman, Politi, Blanchard, & Kaphingst, 2016). Digitally delivered patient education allows for dynamic rather than static content, increasing user engagement, which is a primary goal providers have for their patients (Schweier, Romppel, Richter, & Grande, 2016). Finally, TPE increases patient satisfaction (Stribling & Richardson, 2016), increases compliance (Sohn et al., 2012), and improves health-related quality of life (Lua & Neni, 2013).

To assure the efficacy of TPE efforts, the selection of delivery models or frameworks is an important criterion. Unfortunately, selecting a framework is difficult. Telemedicine frameworks are not widely used (Mohr, Schueller, Montague, Burns, & Rashidi, 2014) or universally agreed upon (van Gemert-Pijnen et al., 2011). While 31 exist, none place emphasis on education, and only 6 of the 31 telemedicine frameworks include, in theory, education as a component (Nepal, Li, Jang-Jaccard, & Alem, 2014). In practice, TPE that is designed to deliver patient-centered, patient-preferred, and patient-managed care is not yet widely available (Chan & Kaufman, 2011). Stand-alone TPE frameworks are unreported in the literature (Gee, Greenwood, Paterniti, Ward, & Miller, 2015). This dearth of information is unfortunate because practitioners and patients agree that TPE, if delivered appropriately, would be cost effective, well received, and a useful health literacy tool for patients with chronic or rare conditions who are medically underserved (Kayser, Kushniruk, Osborne, Norgaard, & Turner, 2015).

While TPE delivery models are scarce, the Community of Inquiry (CoI) encompasses the requisite criteria. It was developed by Garrison, Anderson, and Archer (2001) and is a validated framework from the broader discipline of online learning. A comparison of the elements of the CoI with those of TPE reveals substantial similarities in that both attempt to engage the learner in meaningful, multidimensional educational experiences through the use of remote digital technology (Golding, 2015). The CoI framework was developed to provide a model for successful online education and is comprised of three factors: cognitive presence, social presence, and teaching presence. Scott and Mars (2013) compare the CoI to TPE in the following ways: Cognitive presence refers to information exchange, connection of ideas, application of new ideas, and a sense of curiosity. For TPE, this dimension would apply to the patient's willingness and ability to learn as well as to their learning style. Social presence is the human element of the CoI framework and is comprised of collaboration and risk-free expression. For TPE, this encompasses meaningful interactions between the patient and the providers leading to improved self-management of the patient's medical condition. Finally, teaching presence is comprised of activities that focus on specific information, define or initiate topics, and share personal meaning. For TPE this element focuses on the ability of the providers to offer health information in a way and at a level that patients can understand and act on. Each of these factors is designed to optimize multidimensional online learning experiences and, in TPE, to improve health outcomes.

An accepted online education delivery system framework for TPE would be of use to online health communities (OHCs) that are popular with patients who suffer from chronic conditions or rare disorders and are often medically underserved (Rupert et al., 2014). OHCs are Internet-based discussion forums designed to encourage patients and caregivers to share personal experiences, resources, evidence-based health-related research, and information and provider feedback (Macias, Lewis, & Smith, 2005). While OHCs are generally accepted as a productive resource in the patient community and are increasing rapidly, providers are reluctant to support them out of concern that inaccurate information will be disseminated or that accurate information will be misinterpreted (Léegaré & Witteman, 2013). A standardized TPE framework, similar to the CoI, could remedy this growing divide between patient advantage and provider resistance.

Therefore, the first purpose of the current study was to explore the potential benefits of TPE among online support group patients with rare or chronic conditions. The second purpose of the study was to apply the CoI framework to examine perceptions of TPE among online support group patients with rare or chronic conditions.

1. Methods

The current study used a cross-sectional, anonymous survey design. The A.T. Still University—Arizona Institutional Review Board reviewed and approved the study.

2. Study participants

The target population was patients with rare diseases or chronic illnesses. To reach this target population, patients were recruited from OHCs through Ben's Friends. The mission of Ben's Friends is "to ensure that patients living with rare diseases or chronic illnesses, as well as their caregivers, family, and friends, have a safe and supportive place to connect with others like them" (Ben's Friends, 2017, "Mission"). Ben's Friends has OHCs for 34 different rare diseases or chronic conditions and has approximately 3,000 members internationally.

In collaboration with Ben's Friends, a cover letter and link to an electronic survey was distributed to the members of Ben's Friends during fall 2014. Participation was anonymous and no identifying information was collected. All recruits were adults. Agreeing to participate served as informed consent. Distribution occurred through the Ben's Friends website, Facebook page, and Twitter page. In addition, the directors of each of the OHCs were asked to distribute the survey link to their members. The survey was open for three months, and one reminder was posted to the Ben's Friends website, Facebook page, and Twitter page. Directors of the OHCs could also send a reminder to members at their discretion.

Effective patient education among individuals with rare or chronic conditions is important for health outcomes, but difficult because of patients' evolving needs. TPE may facilitate communication between healthcare professionals and patients to improve health outcomes. This study aimed to explore potential benefits of TPE and to apply the Community of Inquiry (CoI) framework to examine perceptions of TPE among patients with rare or chronic conditions. Patients with rare or chronic conditions were recruited from an international online health community and completed a cross-sectional survey. Patients reported wide access to digital devices and high use of social media tools. While few patients had experienced TPE, most agreed that telemedicine was an excellent medium for patient education. Patients perceived the elements of the CoI framework to be important for effective TPE. Results suggested that TPE meets a number of criteria perceived to be important for patients with rare and chronic conditions, and that the CoI is a viable TPE framework for this population.

2.1. Survey development

A 46-item instrument was developed in collaboration with external subject experts and consultants. The survey, designed to assess patient perceptions of the CoI framework and TPE, underwent seven rounds of revision and was reviewed by specialists in telemedicine and psychology for face and content validity. Demographic questions collected information on age in years, sex, race/ethnicity, education, living situation, country of residence, community of residence (urban, rural, suburban), and average hours worked per week.

Survey items measuring preferences related to TPE were based on the CoI framework (Garrison et al., 2001). Previous work has led to the development of scales to measure the cognitive, social, and teaching presences of the CoI framework (Akyol & Garrison, 2008; Arbaugh et al., 2008; Garrison, Anderson, & Archer, 2010), and the model has been widely applied in online education. Like online education, telemedicine occurs at a distance and often asynchronously. Therefore, for the current study, the authors collaborated with Dr. Randy Garrison, the primary developer of the CoI framework, to modify CoI scales for application to the telemedicine experience. The goal was to determine which elements of the CoI were considered most important to patients during the telemedicine experience. Modification of CoI scale items resulted in 11 items measuring cognitive presence, 8 items measuring social presence, and 11 items measuring teaching presence. For each of the 30 CoI items, a five-point Likert scale was used (1 = not important at all, 2 = not important, 3 = neutral, 4 = important, and 5 = very important). A separate item measured the patient's overall perception of whether telemedicine was an excellent medium for health-related patient education (strongly agree, agree, neutral, disagree, strongly disagree, don't know).

To measure access to digital devices, patients were provided with a list and marked all devices they had easy access to, including smart phone, tablet, laptop, desktop computer, and other. Patients were asked about use of e-mail and which social media tools they used, including Facebook, Twitter, Pinterest, LinkedIn, Skype, Instagram, Tumblr, and other. Patients were also asked if they had experience with using TPE for management of a disease or acute illness, prior to a medical procedure, for follow up to a prior visit, after a medical procedure, or other. Patients with experience using TPE were asked to report which modes they had used: Internet resources or websites, telephone, video conference, computer programs, mobile applications, or other.

2.2. Data collection and analysis

Data were downloaded into SPSS Statistics version 23.0 (IBM Corp., Armonk, NY) for analysis. Mean and standard deviation were calculated for age. For nominal demographic and background characteristics, access to digital devices, use of e-mail, and use of social media tools, frequencies and percentages were calculated. To measure patient preferences for TPE, responses to the CoI items were grouped into four categories: not important or not at all important, neutral, important or very important, and don't know. Frequencies and percentages within each response category were then calculated for each CoI item.

Valid percentages were calculated to measure patients' perceptions of telemedicine as a medium for health-related education. $\chi 2$ tests were used to evaluate whether patient perceptions of telemedicine for health-related education were contingent on their experience with telemedicine for health-related education, sex, race/ethnicity, education, community of residence, and hours worked per week. Kruskal–Wallis analysis of variance was used to compare median ratings of importance of cognitive, social, and teaching presence items between those who had experienced, had not experienced, and did not know if they had experienced TPE.

3. Results

3.1. Summary statistics of study participants

Two hundred ninety-one members of Ben's Friends began the survey. Of these, three cases had missing data for all but one question and were excluded from analyses. An additional respondent who was under 18 and 13 participants who were not patients were also excluded.

Therefore, responses from 274 (9.5% of the total population) participants were included in the analyses. Demographic characteristics of the study participants are presented in Table 1.

Participants were predominantly middle-aged (mean 53.5 ± 12.2 years), female (84%), and White (89%) and had college or postgraduate degrees (78%). Over 80% (*n* = 136) of participants lived in the United States or Canada. The most common community of residence was urban (42%), and 40% of participants were currently employed.

As shown in Figure 1, participants had wide access to digital devices, with smart phones and laptops being the most common. While almost 80% of participants belonged to Facebook, membership in other social media was less common. Fifty-six participants (20%) reported that they had participated in telemedicine sessions for patient education, and among these participants, most had used such sessions for management of a disease or chronic condition (Figure 2). The most common mode used for TPE was Internet resources/websites, followed by telephone, video conference, computer programs, and mobile applications (Figure 3).

3.2. Preferences for telemedicine patient education

Sixty-six (24%) respondents did not answer 20% or more of the CoI items and were excluded from CoI analyses. Therefore, for all CoI analyses, the sample size was 208. While exclusion from CoI analysis was not associated with age, education, community of residence, or hours worked per

Table 1. Demographic and Background Characteristics of Study Participants (N = 274)	
Characteristic	**n (%)**
Agea	
	53.5 (12.2) [21, 85]
Sex	
Female	230 (83.9)
Male	42 (15.3)
Missing	2 (0.7)
Race/ethnicityb	
White	243 (88.7)
Black	11 (4.0)
Hispanic	8 (2.9)
American Indian/Alaskan Native	0
Asian/Pacific Islander	8 (2.9)
Other	4 (1.5)
Missing	4 (1.5)
Highest level of education attained	
Grade school	4 (1.5)
Middle school	2 (0.7)
High school	56 (20.4)
College	138 (50.4)
Postgraduate	73 (26.6)
Missing	1 (0.4)
Community of residence	
Urban (population >50,000)	113 (41.2)
Suburban (population between 25,000–50,000)	86 (31.4)
Rural (population <25,000)	63 (23.0)
Don't know/missing	12 (4.4)
Currently employed	
Yes	110 (40.1)
No	157 (57.3)
Missing	7 (2.6)
Average hours worked per week	
0	157 (57.3)
1–39	43 (15.7)
40	40 (14.6)
>40	27 (9.9)
Missing	7 (2.6)

aAge reported as mean (SD) [minimum, maximum]. bMultiple responses possible; total percentage sums to greater than 100%.

week, males and patients with non-White race/ethnicity were significantly more likely ($p < .05$) to be excluded from CoI analyses because of missing responses.

Tables 2–4 present participating patient preferences for TPE in relation to the CoI items measuring cognitive, social, and teaching presence. Overall, they rated CoI items as important; all items were rated as either important or very important by at least three-fourths of patients in the study. On a five-point scale, the average rating of importance across cognitive presence items was 4.6

Figure 1. Access to digital devices and use of social media tools (*N* = 274).
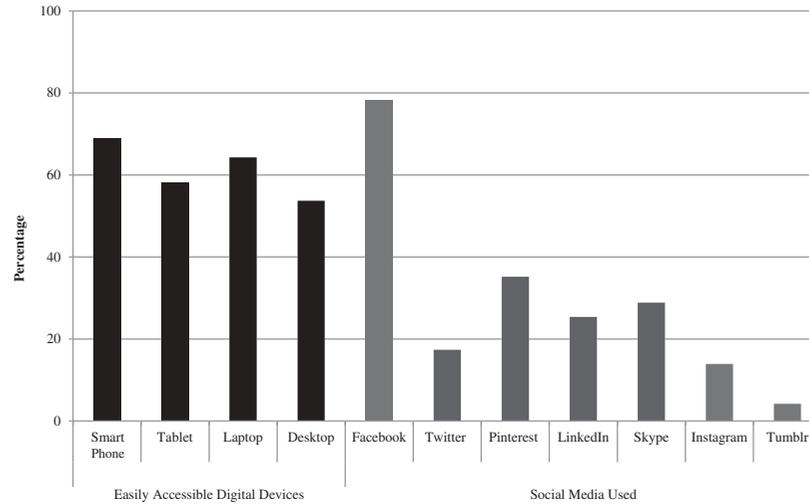Note. Patients could mark more than one response.

Figure 2. Reasons for use of telemedicine for health-related education for patients who have used telemedicine (*n* = 56).
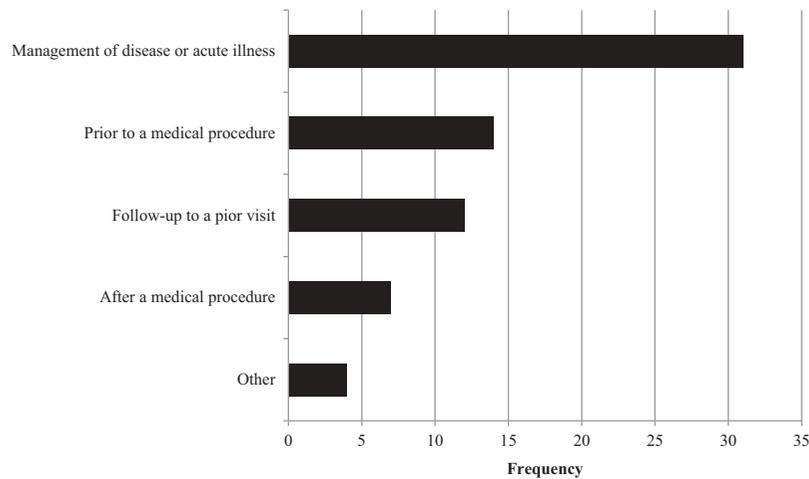Note. Patients could mark more than one response.

Figure 3. Modes used by patients who have experienced telemedicine for patient education (*n* = 56).
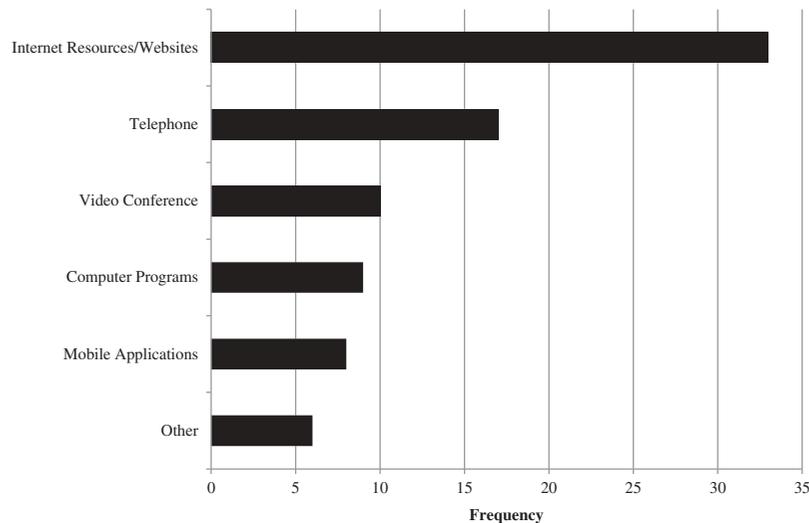Note. Patients could mark more than one response.

cogent··medicine

Table 2. Patient Perceptions of Cognitive Presence Items (*n* = 208)				
	n (%) Not Important or Not at All Important	*n* (%) Neutral	*n* (%) Important or Very Important	*n* (%) Don't Know
How important is it that:				
Your interest in health-related issues increases	9 (4.2)	32 (14.9)	173 (80.5)	1 (0.5)
Your curiosity in health-related issues increases	10 (4.7)	37 (17.2)	167 (77.7)	1 (0.5)
You feel motivated to learn and get more health-related information	7 (3.3)	20 (9.1)	187 (87.4)	0
You use more than one source to explore health-related problems	2 (0.9)	28 (13.0)	183 (85.1)	2 (0.9)
You get information to answer your questions	0	4 (1.9)	209 (98.1)	0
You feel that your provider respects your point of view	0	11 (5.1)	203 (94.9)	0
You get up-to-date information to answer your health questions	1 (0.5)	3 (1.4)	212 (98.1)	0
Learning activities aim to help you find answers about your health	3 (1.4)	13 (6.0)	200 (92.6)	0
You are given basic ideas about your health	2 (0.9)	26 (12.1)	187 (87.0)	0
You can use what you have learned to improve your health	1 (0.5)	7 (3.3)	207 (96.3)	0
You use the information to find answers about your health on your own	2 (0.9)	19 (8.9)	193 (90.2)	0

Note. Valid percentages are presented.

(median = 4.5, interquartile range = 4.2–4.9). The mean across social presence items was 4.5 (median = 4.5, interquartile range = 4.2–5.0), and the mean across teaching presence items was also 4.5 (median = 4.5, interquartile range = 4.3–4.9).

For cognitive presence (Table 2), the items rated most important were getting information to answer questions (98.1%), getting up-to-date information (98.1%), and the ability of patients to use what they had learned to improve their health (96.3%). The lowest rated item was related to increased patient curiosity about health-related issues (77.7%).

The social presence items rated most important were being comfortable with two-way discussions (93.5%), being able to disagree with the provider but still feeling a sense of trust (95.4%), and feeling that the patient and provider worked as a team (95.3%) (Table 3). The social presence item rated lowest was related to the provider giving the patient a sense of belonging to the practice (79.5%).

The items rated most important for teaching presence were the provider clearly communicating important topics (98.2%), clearly communicating important goals (95.4%), and helping the patient understand topics and clarify thinking (95.8%). The item rated as least important was the provider reinforcing the patient's feeling of belonging and importance (77.9%) (Table 4).

Table 3. Patient Perceptions of Social Presence Items (*n* = 208)				
	n (%) Not Important or Not at All Important	*n* (%) Neutral	*n* (%) Important or Very Important	Don't Know
How important is it that the healthcare provider:				
Gives you a sense of belonging to the practice	17 (7.9)	26 (12.1)	171 (79.5)	1 (0.5)
How important is it that you feel comfortable:				
Forming a clear impression of your healthcare provider	1 (0.5)	14 (6.5)	200 (93.0)	0
Using the technology	1 (0.5)	18 (8.3)	198 (91.2)	0
With the two-way discussions	1 (0.5)	11 (5.1)	202 (93.5)	2 (0.9)
Speaking with the provider electronically	5 (2.3)	24 (11.1)	187 (86.6)	0
Being able to disagree with the provider but still feeling a sense of trust	1 (0.5)	9 (4.2)	206 (95.4)	0
How important would it be that: Your point of view is heard and accepted	1 (0.5)	15 (6.9)	200 (92.6)	0
You and the provider work as a team	0	10 (4.7)	205 (95.3)	0

Valid percentages are presented.

Table 4. Patient Perceptions of Teaching Presence Items (*n* = 208)				
	n (%) Not Important or Not at All Important	*n* (%) Neutral	*n* (%) Important or Very Important	Don't Know
How important is it that the healthcare provider:				
Clearly communicates important topics	0	3 (1.4)	213 (98.2)	1 (0.5)
Clearly communicates important goals	1 (0.5)	8 (3.7)	206 (95.4)	1 (0.5)
Provides clear instructions for learning activities	0	11 (5.1)	205 (94.5)	1 (0.5)
Identifies areas that help you learn	2 (0.9)	11 (5.1)	197 (92.1)	4 (1.9)
Helps you understand the topics and clarify your thinking	4 (1.9)	5 (2.3)	206 (95.8)	0
Keeps you engaged	7 (3.3)	8 (3.8)	195 (92.4)	1 (0.5)
Helps you stick to goals and learn	5 (2.3)	25 (11.6)	184 (85.2)	2 (0.9)
Encourages you to explore new health-related ideas	5 (2.3)	30 (14.0)	178 (83.2)	1 (0.5)
Reinforces your feeling of belonging and importance	16 (7.4)	31 (14.3)	169 (77.9)	1 (0.5)
Focuses on relevant issues to help you learn	1 (0.5)	14 (6.5)	200 (92.2)	2 (0.9)
Provides feedback that helps you	0	11 (5.0)	205 (94.0)	2 (0.9)

Valid percentages are presented.

Table 5. Ratings of Importance of Cognitive, Social, and Teaching Presence by Experience with Telemedicine for Patient Education (*n* = 208)

	Experience with Telemedicine for Patient Education			
	Yes	**No**	**Don't Know**	
	(*n* = 36)	**(*n* = 150)**	**(*n* = 19)**	***p* Value**
Cognitive presence, median (IQR)	4.4 (4.1–5.0)	4.5 (4.2–5.0)	4.6 (4.2–5.0)	.72
Social presence, median (IQR)	4.4 (4.0–4.9)	4.6 (4.3–4.9)	4.5 (4.3–4.9)	.40
Teaching presence, median (IQR)	4.5 (4.1–4.9)	4.7 (4.3–5.0)	4.6 (4.4–4.9)	.34

p values based on Kruskal–Wallis analysis of variance. IQR = interquartile range. Possible responses: 1 = not important at all, 2 = not important, 3 = neutral, 4 = important, and 5 = very important.

Kruskal–Wallis analysis of variance comparing median ratings of importance across cognitive, social, and teaching presence items between those who had experienced, had not experienced, and did not know if they had experienced TPE revealed no significant differences (Table 5).

When asked if telemedicine was an excellent medium for health-related education, 67% of patients responded "agree" or "strongly agree" (Figure 4). Among patients who had experience with TPE, 86% agreed or strongly agreed that telemedicine was an excellent medium for health-related education compared with 69% of patients who had not experienced or did not know if they had experienced TPE, $\chi2$ (1, 195) = 3.83, *p* = .05. Attitudes about telemedicine as a medium for health-related education did not differ significantly (*p* > .05) by age, sex, race/ethnicity, education, community of residence, or hours worked per week.

4. Discussion

Results of the current study suggested that patients with rare and chronic conditions were interested in greater professional collaboration, disease knowledge, management, and education. Ben's Friends, the online patient support community for rare and chronic conditions used for this study's target population, has experienced sustained success and continuous growth demonstrating the desire, by patients, for additional digital connection and communication.

Further, the geographic diversity of Ben's Friends membership is broad; in 2016, there were 100,000 site visits monthly, including hits from every U.S. state and countries around the world (Ben's Friends, 2017, "History"). This geographic diversity and breadth of membership suggests that TPE may be an accessible and acceptable digital delivery communication method for patients with access to and literacy in computing technology.

Figure 4. Participant responses to the survey item asking if telemedicine is an excellent medium for health-related education.
Note. Missing cases not shown; valid cases *n* = 195. Valid percentages are reported.

cogent ·· medicine
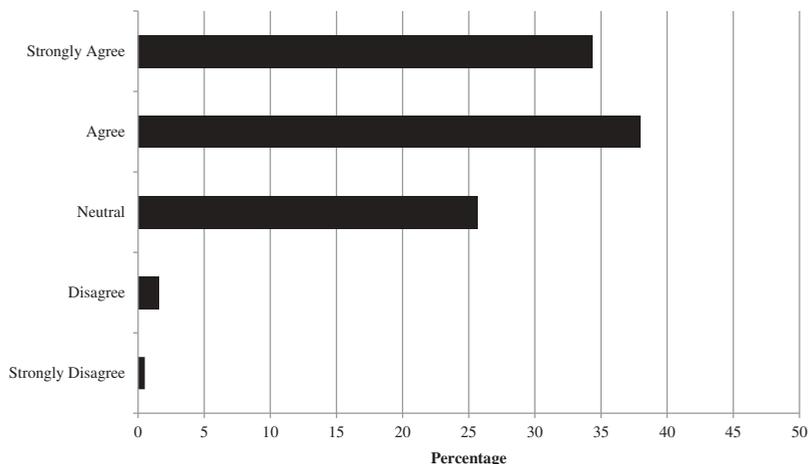
The first purpose of the current study was to explore the potential of TPE among online support group patients with rare or chronic conditions. The results supported the potential of TPE in the target population in several ways. First, patients had access to multiple digital devices, with smart phones being the most common. This finding is supported by the Pew Research Center (2017), which found that 80% of Americans own some type of (noncellular) digital device. In addition, it was reported that 95% of the adult U.S. population owned a cellphone, and 77% owned smart-phones (Pew Research Center, 2017). This study's demographic findings also mirrored Pew report findings in that smartphone ownership dropped to 48% in the over 65 age group. With easy access to and active use of digital devices and smartphones, TPE can be an excellent method of delivery to a large portion of the rare and chronic condition patient population.

Results of the current study also supported the potential of TPE because participants indicated that they commonly used social media tools. This finding reflects those of the National Archives (2017a), which reported that 97% of adults in the U.S. have direct or indirect access to social media networks and the majority have personal accounts. On average, according to the National Archives (2017b), U.S. adults devote two hours daily to social media networking, messaging, and informa-tion gathering. This willingness to use and subscribe to social media platforms demonstrates an exceptional opportunity for TPE delivery.

Currently, as supported by results of the current study, the most common social media network used by U.S. adults is Facebook. Neilson (Casey, 2017) reports that 68% of all U.S. adults have a Facebook subscription, and almost 100% of all public and private companies, agencies, and organizations have a Facebook site. Personal usage and site activity is brisk. This devotion to Facebook; its user friendly, free platform; and its ability to easily link followers to other sites make it an excellent prospect for an effective TPE environment.

The use of TPE as a viable method for patient education delivery through digital devices and social media platforms was supported by the current study findings. Of the participants who had experience with TPE, most used it for management of conditions through Internet resources and websites or by telephone. These findings are consistent with previous research that found patients wanted more information about their condition and access to that information through the Internet, social media networks, and smartphone applications (AlHilali, AlMuammar, AlKahtani, Khandekar, & AlJasser, 2016; Huang et al., 2015; Shea et al., 2009). It is likely these choices were overwhelmingly selected as a way to access desired information at a pace and in a place that allowed for privacy and time to reflect. Patients in these studies also indicated that having the opportunity to access user-friendly, accurate information about their condition empowered them to ask better questions of their medical provider and resulted in improved compliance (AlHilali et al., 2016; Huang et al., 2015; Shea et al., 2009).

On a broader level, while few patients in the current study had experience with TPE, the majority agreed that telemedicine was an excellent medium for patient education. This perception may be due to the common characteristics of digital communication that patients value, such as commitment to user friendliness and readability. According to Eltorai, Sharma, Wang, and Daniels (2015) and to Polishchuck, Hashem, and Sabharwal (2012), these two factors make TPE a preferred delivery method for health-related patient education. By its nature, social media is designed to encourage repeated and sustained virtual visits. Competition for customers or clients is fierce. Therefore, great effort and focus is placed on providing users with an attentive, centered, and friendly experience. A typical example of a user-attentive experience is automatic recognition of name and display of past activity. A user-centered experience is focused on offering what the client wants based on stated preferences, and a user-friendly experience ensures ease of operation. Despite claims to the contrary, this emphasis on digital communication for health-related patient education in the field of medicine and patient education is fairly unique (Svavarsdóttir, Sigurðoardóottir, & Steinsbekk, 2015). In fact, only a small minority of medical practices, large and small, offer

such opportunities (Anderson, 2015). In addition, most Internet and web-based sites, including social media networks, aim to present information at an elementary grade reading level with an emphasis on visuals, which typically include photos and videos. A systematic review by Eltorai et al. (2015) revealed that most traditional patient education material was presented well above the patient-preferred sixth grade reading level and without compelling or engaging visual support.

The second purpose of the current study was to apply the CoI framework to examine perceptions of TPE among online support group patients with rare or chronic conditions. Not surprisingly, when asked about the three elements of the CoI framework, most participants rated the presence of all three as important for effective use and delivery of TPE. For cognitive presence, participants specifically wanted up-to-date information to answer their health questions and indicated that they intended to use information received to improve their health. For social presence, participants perceived two-way communication and teamwork to be important. For teaching presence, participants most wanted the provider to clearly communicate important topics. Overall, when asked if telemedicine was an excellent medium for health-related education, most patient participants thought that it was. This result applied to those who had experienced telemedicine and to those who had not. Further, these findings are consistent with previous patient satisfaction studies (Moore, Hamilton, Krusel, Moore, & Pierre-Louis, 2016; Tehrani, Feldman, Camacho, & Balkrishnan, 2011). Of particular note, in the current study, for the social presence category, patients also indicated that user friendly technology was important. This finding, along with those for teaching and cognitive presences, reinforces the value of TPE and the potential of the CoI as a framework for TPE.

The current study had several limitations. Demographic variables were imbalanced, participants were predominantly White, educated women from the U.S. and Canada and likely did not represent most medically underserved patients. Also, there was no operationalized criterion against which to test CoI items to determine validity or reliability. In addition, two different sets of patients were included, those with chronic and medically rare conditions. It is possible that these two groups have divergent needs and interests. Conversely, study strengths included use of an established framework to better inform and direct TPE and a method by which medical practitioners can narrow the information and communication gap for the growing number of medically underserved patients with rare or chronic conditions.

In conclusion, results of the current study suggested that TPE meets a number of criteria perceived to be important for patients with rare and chronic conditions. Further, patients were willing, under certain conditions, to use telemedicine patient education as a digital delivery method for rare disease and chronic condition education. Finally, the CoI, along with its three presences, appeared to be viable framework for this population and warrants further examination.

Author details
Joan S Leafman[1]
E-mail: jleafman@atsu.edu
Kathleen Mathieson[1]
E-mail: kmathieson@atsu.edu
[1] College of Graduate Health Studies, Still Research Institute Scientist, A.T. Still University, 5850 E. Still Circle, Mesa, AZ 85206.

References
Akyol, Z., & Garrison, D. R. (2008). The development of a Community of Inquiry over time in an online course: Understanding the progression and integration of social, cognitive, and teaching presence. *Journal of Asynchronous Learning Networks*, *12*(3–4), 3–22.
AlHilali, S. M., AlMuammar, A. M., AlKahtani, E., Khandekar, R., & AlJasser, A. A. (2016). Preferred method of education among patients in ophthalmic care in Saudi Arabia. *Middle East African Journal of Ophthalmology*, *23*, 168–171. doi:10.4103/0974-9233.171780
Anderson, M. (2015, October 29). Technology device ownership: 2015. Retrieved from http://www.pewin

cogent ••medicine

ternet.org/2015/10/29/technology-device-owner ship-2015/.

Arbaugh, J. B., Cleveland-Innes, M., Diaz, S. R., Garrison, D. R., Ice, P., Richardson, J. C., & Swan, K. P. (2008). Developing a Community of Inquiry instrument: Testing a measure of the Community of Inquiry framework using a multi-institutional sample. *Internet and Higher Education, 11*, 133–136. doi:10.1016/j. iheduc.2008.06.003

Banbury, A., Parkinson, L., Nancarrow, S., Dart, J., Gray, L., & Buckley, J. (2014). Multi-site videoconferencing for home-based education of older people with chronic conditions: The telehealth literacy project. *Journal of Telemedicine and Telecare, 20*, 353–359. doi:10.1177/1357633X14552369

Ben's Friends. (2017). Retrieved from http://www.bens friends.org/.

Bombeke, K., Symons, L., Vermeire, E., Debaene, L., Schol, S., De Winter, B., & Van Royen, P. (2012). Patient-centeredness from education to practice: The "lived" impact of communication skills training. *Medical Teacher, 34*, 338–348. doi:10.3109/0142159X.2012.670320

GovTrack. (2002). H.R. 4013 (107th): Rare diseases act of 2002. Retrieved from https://www.govtrack.us/con gress/bills/107/hr4013/text. doi: 10.1044/1059-0889 (2002/er01)

Casey, S. (2017, January 17). 2016 Neilson social media report. Retrieved from http://www.nielsen.com/us/en/insights/reports/2017/2016-nielsen-social-media-report.html.

Chan, C. V., & Kaufman, D. R. (2011). A framework for characterizing eHealth literacy demands and barriers. *Journal of Medical Internet Research, 13*, 439–454. doi:10.2196/jmir.1750

Davis, S. W., & Oakley-Girvan, I. (2015). mHealth education applications along the cancer continuum. *Journal of Cancer Education, 30*, 388–394. doi:10.1007/s13187-014-0761-4

Eltorai, A. E., Sharma, P., Wang, J., & Daniels, A. H. (2015). 'Most American academy of orthopaedic Surgeons' online patient education material exceeds average patient reading level. *Clinical Orthopaedics and Related Research, 10*, 1181–1186. doi:10.1007/s11999-014-4071-2

Garrison, D. R., Anderson, T., & Archer, W. (2001). Critical thinking, cognitive presence, and computer conferencing in distance education. *American Journal of Distance Education, 15*, 7–23. doi:10.1080/08923640109527071

Garrison, D. R., Anderson, T., & Archer, W. (2010). The first decade of the Community of Inquiry framework: A retrospective. *Internet and Higher Education, 13*, 5–9. doi:10.1016/j.iheduc.2009.10.003

Gee, P. M., Greenwood, D. A., Paterniti, D. A., Ward, D., & Miller, L. M. (2015). The eHealth enhanced chronic care model: A theory derivation approach. *Journal of Medical Internet Research, 17*, 86–103. doi:10.2196/jmir.4067

Golding, C. (2015). The Community of Inquiry: Blending philosophical and empirical research. *Studies in Philosophy and Education, 34*(2), 205–216. doi:10.1007/s11217-014-9420-9

Goodman, R. A., Posner, S. F., Huang, E. S., Parekh, A. K., & Koh, H. K. (2013). Defining and measuring chronic conditions: Imperatives for research, policy, program, and practice. *Preventing Chronic Disease, 10*, E66. doi:10.5888/pcd10.120239

Huang, G., Fang, C. H., Agarwal, N., Bhagat, N., Eloy, J. A., & Langer, P. D. (2015). Assessment of online patient education materials from major ophthalmologic

associations. *JAMA Ophthalmology, 133*, 449–454. doi:10.1001/jamaophthalmol.2014.6104

Jardins, T. D., Drone, S. A., Hashisaka, S., Hazzard, J., Hunt, S. B., Massey, K., & Turske, S. (2015). Patient engagement and activation in three underserved beacon communities. *Journal of Health Care for the Poor and Underserved, 26*, 777–783. doi:10.1353/hpu.2015.0084

Jensen, O., Gabre, P., Sköld, U. M., Birkhed, D., & Povlsen, L. (2014). 'I take for granted that patients know': Oral health professionals' strategies, considerations and methods when teaching patients how to use fluoride toothpaste. *International Journal of Dental Hygiene, 12*, 81–88. doi:10.1111/idh.12041

Kayser, L., Kushniruk, A., Osborne, R. H., Norgaard, O., & Turner, P. (2015). Enhancing the effectiveness of consumer-focused health information technology systems through eHealth literacy: A framework for understanding users' needs. *JMIR Human Factors, 2*, e9. doi:10.2196/humanfactors.3696

Léegaré, F., & Witteman, H. O. (2013). Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health Affairs, 32*, 276–284. doi:10.1377/hlthaff.2012.1078

Lua, P. L., & Neni, W. S. (2013). Health-related quality of life improvement via telemedicine for epilepsy: Printed versus SMS-based education intervention. *Quality of Life Research, 22*, 2123–2132. doi:10.1007/s11136-013-0352-6

Macias, W., Lewis, L. S., & Smith, T. L. (2005). Health-related message boards/chat rooms on the web: Discussion content and implications for pharmaceutical sponsorships. *Journal of Health Communication, 10*(3), 209–223. doi:10.1080/10810730590934235

Mohr, D. C., Schueller, S. M., Montague, E., Burns, M. N., & Rashidi, P. (2014). The behavioral intervention technology model: An integrated conceptual and technological framework for eHealth and mHealth interventions. *Journal of Medical Internet Research, 16*, e146. doi:10.2196/jmir.3077

Moore, A. D., Hamilton, J. B., Krusel, J. L., Moore, L. G., & Pierre-Louis, B. J. (2016). Patients provide recommendations for improving patient satisfaction. *Military Medicine., 181*, 356–363. doi:10.7205/MILMED-D-15-00258

National Archives. (2017a). Social media and digital engagement. Retrieved from http://www.archives.gov/social-media/.

National Archives. (2017b). Social media statistics. Retrieved from https://www.archives.gov/social-media/reports.

Nepal, S., Li, J., Jang-Jaccard, J., & Alem, L. (2014). A framework for telehealth program evaluation. *Telemedicine and e-Health, 20*, 393–404. doi:10.1089/tmj.2013.0093

Pew Research Center. (2017, January 12). Mobile fact sheet. Retrieved from http://www.pewinternet.org/fact-sheet/mobile/.

Polishchuck, D. L., Hashem, J., & Sabharwal, S. (2012). Readability of online patient education materials on adult reconstruction web sites. *Journal of Arthroplasty, 27*, 716–719. doi:10.1016/j.arth.2011.08.020

Rodriguez de Bittner, M., & Zaghab, R. W. (2011). Improving the lives of patients with chronic diseases: Pharmacists as a solution. *Journal of Health Care for the Poor and Underserved, 22*, 429–436. doi:10.1353/hpu.2011.0044

Ross, A., Ohlsson, U., Blomberg, K., & Gustafsson, M. (2015). Evaluation of an intervention to individualise patient education at a nurse-led heart failure clinic: A

mixed-method study. *Journal of Clinical Nursing, 24,* 1594–1602. doi:10.1111/jocn.12760

Rupert, D. J., Moultrie, R. R., Read, J. G., Amoozegar, J. B., Bornkessel, A. S., O'Donoghue, A. C., & Sullivan, H. W. (2014). Perceived healthcare provider reactions to patient and caregiver use of online health communities. *Patient Education and Counseling, 96,* 320–326. doi:10.1016/j.pec.2014.05.015

Sav, A., King, M. A., Kelly, F., McMillan, S. S., Kendall, E., Whitty, J. A., & Wheeler, A. J. (2015). Self-management of chronic conditions in a rural and remote context. *Australian Journal of Primary Health, 21,* 90–95. doi:10.1071/PY13084

Schweier, R., Romppel, M., Richter, C., & Grande, G. (2016). Dissemination strategies and adherence predictors for web-based interventions: How efficient are patient education sessions and email reminders? *Health Education Research, 31,* 384–394. doi:10.1093/her/cyw019

Scott, R. E., & Mars, M. (2013). Principles and framework for eHealth strategy development. *Journal of Medical Internet Research, 15,* e155. doi:10.2196/jmir.2250

Seo, J., Goodman, M. S., Politi, M., Blanchard, M., & Kaphingst, K. A. (2016). Effect of health literacy on decision-making preferences among medically underserved patients. *Medical Decision Making, 36,* 550–556. doi:10.1177/0272989X16632197

Shaha, M., Wüthrich, E., Stauffer, Y., Herczeg, F., Fattinger, K., Hirter, K., & Herrmann, L. (2015). Implementing evidence-based patient and family education on oral anticoagulation therapy: A community-based participatory project. *Journal of Clinical Nursing, 24,* 1534–1545. doi:10.1111/jocn.12743

Shea, S., Weinstock, R. S., Teresi, J. A., Palmas, W., Starren, J., & Cimino, J. J.; IDEATel Consortium. (2009). A randomized trial comparing telemedicine case management with usual care in older, ethnically diverse, medically underserved patients with diabetes mellitus: 5 Year results of the IDEATel study. *Journal of the American Medical Informatics Association, 16,* 446–456. doi:10.1197/jamia.M3157

Shipman, J. P., Lake, E. W., Van der Volgen, J., & Doman, D. (2016). Provider documentation of patient education: A lean investigation. *Journal of the Medical Library Association, 104,* 154–158. doi:10.3163/1536-5050.104.2.012

Sohn, S., Helms, T. M., Pelleter, J. T., Müller, A., Kröttinger, A., & Schöffski, O. (2012). Costs and benefits of personalized healthcare for patients with chronic heart failure in the care and education program "Telemedicine for the Heart". *Telemedicine and e-Health, 18,* 198–204. doi:10.1089/tmj.2011.0134

Stellefson, M., Chaney, B., Ochipa, K., Chaney, D., Haider, Z., Hanik, B., & Bernhardt, J. M. (2014). YouTube as a source of chronic obstructive pulmonary disease patient education: A social media content analysis. *Chronic Respiratory Disease, 11,* 61–71. doi:10.1177/1479972314525058

Stribling, J. C., & Richardson, J. E. (2016). Placing wireless tablets in clinical settings for patient education. *Journal of the Medical Library Association, 104,* 159–164. doi:10.3163/1536-5050

Svavarsdóottir, M. H., Sigurðoardóottir, Á. K., & Steinsbekk, A. (2015). How to become an expert educator: A qualitative study on the view of health professionals with experience in patient education. *BMC Medical Education, 15,* 87. doi:10.1186/s12909-015-0370-x

Tamura-Lis, W. (2013). Teach-back for quality education and patient safety. *Urologic Nursing, 33*(6), 267–271, 298.

Tehrani, A. B., Feldman, S. R., Camacho, F. R., & Balkrishnan, R. (2011). Patient satisfaction with outpatient medical care in the United States. *Health Outcomes Research in Medicine, 2,* el97–e202. doi:10.1016/j.ehrm.2011.09.001

Torenholt, R., Varming, A., Engelund, G., Vestergaard, S., Møller, B. L., Pals, R. A., & Willaing, I. (2015). Simplicity, flexibility, and respect: Preferences related to patient education in hardly reached people with type 2 diabetes. *Patient Preference and Adherence, 9,* 1581–1586. doi:10.2147/PPA.S91408

University of Texas Medical Branch. (2014). *UTMB handbook of operating procedures* (Policy 9.3.4). Retrieved from https://www.utmb.edu/policies_and_procedures/IHOP/Clinical/Patient_Rights/IHOP%20%2009.03.04%20-%20Patient%20Family%20Education.pdf

van Gemert-Pijnen, J. E., Nijland, N., van Limburg, M., Ossebaard, H. C., Kelders, S. M., Eysenbach, G., & Seydel, E. R. (2011). A holistic framework to improve the uptake and impact of eHealth technologies. *Journal of Medical Internet Research, 13,* 43–61. doi:10.2196/jmir.1672

Cogent Medicine (ISSN: 2331-205X) is published by Cogent OA, part of Taylor & Francis Group.

Publishing with Cogent OA ensures:

- Immediate, universal access to your article on publication
- High visibility and discoverability via the Cogent OA website as well as Taylor & Francis Online
- Download and citation statistics for your article
- Rapid online publication
- Input from, and dialog with, expert editors and editorial boards
- Retention of full copyright of your article
- Guaranteed legacy preservation of your article
- Discounts and waivers for authors in developing regions

Submit your manuscript to a Cogent OA journal at www.CogentOA.com