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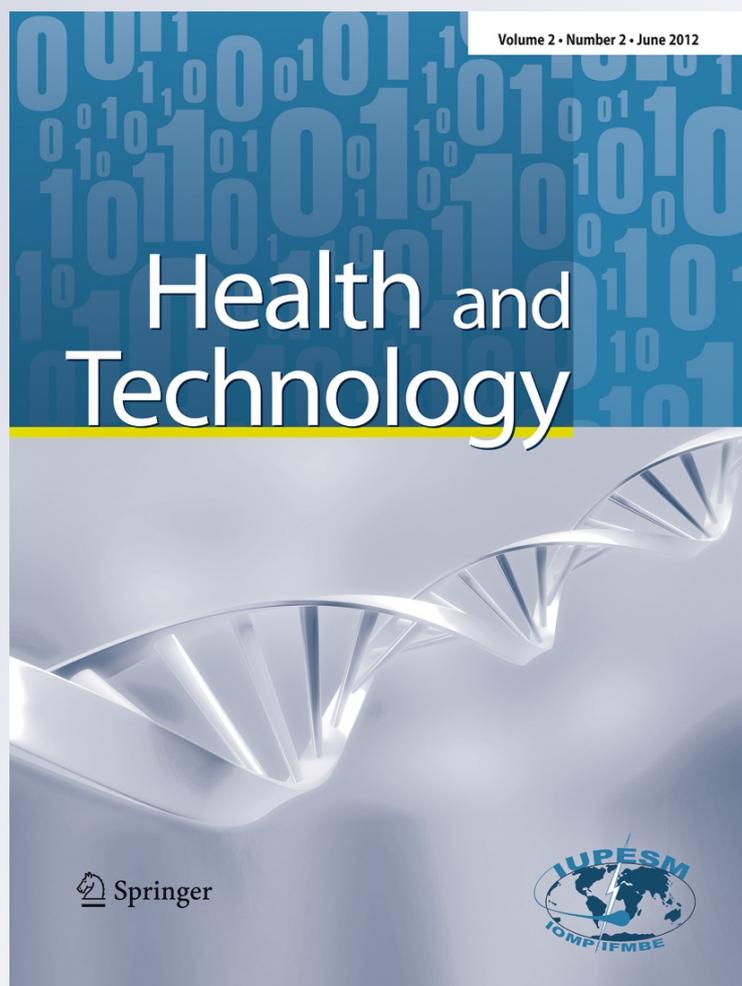
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What patients want: relevant health information technology for diabetes self-management

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Abstract Health information technology has great potential to promote efficiency in patient care and increase patient-provider communication, and patient engagement in their treatment. This paper explored qualitatively what patients with type 2 diabetes want from electronic resources that are designed to support their diabetes self-management. Data were collected via interviews and focus groups from managed care patients who had completed participation in either a web-based (MyPath) or in-person group-based (¡Viva Bien!) longitudinal diabetes self-management study. Content analysis identified common themes that highlighted participant interest in virtual and electronic programs to support diabetes self-management goals, and their desired content and features. Eighteen ¡Viva Bien! participants completed telephone interviews and 30 MyPath participants attended seven focus groups in 2010–2011. All participants expressed a preference for face-to-face contact; however, most participants were also interested in using technology as a tool to support daily diabetes self-management decisions

and to receive tailored information. Choice of technology, personalized instruction on how to use program features, and the ability to exchange information with their healthcare team were desired by all participants. Participants were divided on whether virtual social support networks should be closed to friends and family, should include other program members (peers), or should be open to anyone with diabetes. Participants aged 65 and older stressed the desire for technical support. What patients wanted from technology is real-time assistance with daily behavioral decision-making, ability to share information with their healthcare team, connections with others for support, and choice.

Keywords Technology · Diabetes · Self-management · Health behavior change

1 Introduction

The Internet and availability of e-health interventions and resources offer promise for assisting adults with diabetes to maintain health behaviors [1]. With the increase in the number of people living with diabetes [2–4]; and with annual diabetes-related costs expected to increase to \$192 billion by 2020 [5], the demand for diabetes services far surpasses the time available in most primary care practices [6, 7]. E-health technology could help relieve the strain [8].

Most diabetes management happens outside of clinics [9] yet patients look to healthcare providers for counseling and support. Unfortunately, due to limitations in staffing and reimbursement, counseling patients on diet, exercise, and other important self-management behaviors is not accomplished as part of routine primary care [10, 11]. Research shows that in-person interventions can improve behavioral and biologic outcomes [12–15], but questions remain about

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whether their relatively high cost might be reduced using technology without limiting their effectiveness. Well-designed, patient-centered [8, 16–18] e-health technologies could enhance access to diabetes self-management programs and promote dissemination [19, 20].

1.1 Advantages of e-health technology

Advantages include portability, timeliness, efficiency [21], scalability [22–24], and few barriers based on geography or mobility [25]. E-health programs can be tailored [26], can deliver support as needed [21] and prevent relapse [27–31], increase access to healthcare professionals, and may lower healthcare costs [23, 32]. With the introduction of the patient-centered medical home (PCMH) [16], opportunities exist for behavioral scientists to work with healthcare practices to design electronic technologies to achieve practice and patient goals [33].

1.2 Use of electronic programs to improve health behaviors

Patients with diabetes are responsible for self-management (e.g., eating a healthful diet, engaging in regular physical activity, taking prescribed medications) to help them avoid complications [34] and risk of cardiovascular disease [35–38]. With few exceptions [23] research has demonstrated improvements in diabetes outcomes and chronic illness self-management behaviors [32, 39–41] when behavioral support is available through a variety of technologies (e.g., cell phone and automated text messaging [39, 42–45], hand-held devices [46] and e-communication with healthcare providers [47, 48]). E-health interventions have helped improve dietary practices [23, 49], physical activity [28, 50, 51], medication taking [32, 49, 52], clinical outcomes [32, 39, 40, 53, 54], and psychosocial variables [55].

1.3 Use of electronic programs to access support and resources

Use of social networking services (SNS) [23] has nearly doubled since 2008, with fastest growth reported among Internet users ages 50–64 and females [56]. Studies suggest that online support groups have positive effects on perceived social support as well as on behavioral and clinical outcomes [57]. Recent studies of e-health technology [58, 59] found that patients desire real-time tailored support from other study participants and healthcare providers.

1.4 Reach of e-health interventions

E-health technology has the potential to help assure that interventions reach individuals in need of tailored support [60, 61] or when geographic barriers and health services

limitations reduce access to health-related programs and services [62]. People older than age 60 with low incomes or less education are less likely to be online [63], but Internet use is rising among these groups [23], in part due to the widespread adoption of web-enabled mobile phones [64]. To improve health outcomes for vulnerable populations [65, 66], Internet-delivered behavioral change programs must consider age [59, 67, 68], ethnicity [32, 63, 64, 69–77], literacy levels [59, 78–80], and gender [68, 81]. Slower adoption of mobile technology by American Indians/Alaska Natives (AI/AN) has been reported—likely due to rural connectivity issues [71]. A recent pilot web-based diabetes self-management study exploring ethnicity and mobile technology adoption, compared AI/AN to non-AI/AN participants. The study found that the AI/AN who were more frequent users were slightly younger, had less formal education, weighed more, were more depressed, and had more hypoglycemic symptoms. AI/AN participants expressed a strong preference for an “all-AI/AN” website [72, 73].

1.5 Barriers to Internet use

The healthcare sector has been slow to embrace information technology [82]. However, as adoption of electronic health records spreads, along with increased incentives and regulations to promote their meaningful use [21], patients are experiencing increased opportunities to communicate with their doctor [83], view their health information, and receive health promotion information [84–87] electronically. Barriers to website use include fear of loss of privacy, intrusiveness, cost, and loss of interest over time [58]. Engagement with health related programs could be enhanced by providing patients with feedback that is frequent, tailored, interesting, encouraging, nonjudgmental, and unpredictable [58, 81, 88]. In addition, inclusion of self-monitoring features, such as tracking minutes of exercise, can increase engagement [88] and enhance goal achievement [89].

1.6 Added value of human contact

The value of using health information technology (HIT) to provide support for chronic disease self-management, may be limited if it does not include human contact from healthcare providers or social support networks [81, 84, 90]. The ideal combination of human contact and technology has not been thoroughly explored [23, 61, 91, 92]. Reported attrition rates vary widely in studies of e-health interventions with and without human contact. For example, Rabin and Glasgow, in their report on implementation studies of interactive health communication applications described attrition rates as low as 3% for an interactive web-based intervention that included live telephone counseling, and attrition as high as 65% for a publically available web-based smoking

cessation intervention that lacked personalized human follow-up [61]. E-health interventions with human contact may be more effective than technology-only interventions, but more research is needed [8, 90].

1.7 Study purpose

Surprisingly little is known about the preferences and characteristics of patients for whom e-health applications are intended. This paper analyzes qualitative data collected from two recent clinical trials with type 2 diabetes patients, to better understand patient likes and dislikes with regard to using health information technology as a tool for diabetes self-management. Inclusion of patients who had recently been exposed to an electronic or a non-electronic diabetes self-management program provided context for our qualitative focus groups and interviews, allowing patients to think about how they would use technology for a specific health-related purpose. Thus, while the content areas were established a priori, the themes that emerged are potentially generalizable to a broader range of HIT applications. In particular we explored features of telephone and Internet-based programs to understand what would be useful to supporting their health behavior goals, and what aspects of in-person encounters with clinical staff, within the context of diabetes self-management support, could be augmented or replaced by technology. We also explored how technology could be used to connect with peers, friends and family, to get support for changing their health behavior. The results provide answers to questions relevant to both researchers and practitioners seeking to design interventions that are convenient, acceptable, and useful [93]. Our specific research questions were: How comfortable were patients in using technology as a tool to support their diabetes self-management, particularly if it replaced some encounters with human beings? How did patients view using technology as a way to share diabetes self-management information with their healthcare providers and social support networks? What would improve the user-friendliness of health information technology? In what ways would patients use electronic resources or tools to help them manage their specific health behaviors such as eating, physical activity, and medication taking?

2 Methods

2.1 Participants

Participants were managed-care patients in two different type 2 diabetes self-management intervention studies: ¡Viva Bien! and MyPath. Details of these studies, including in-

depth descriptions of the interventions and quantitative findings are published elsewhere [14, 30, 89, 94, 95]. In brief, MyPath tested a minimal human contact, 12-month web-based self-management intervention designed to provide electronic support for adults with type 2 diabetes to improve their eating, physical activity, and medication-taking behaviors [30]. The program was largely stand-alone, and participant engagement declined over time [89]. ¡Viva Bien! tested a 24-month in-person, group-based intervention for Latinas with type 2 diabetes to improve diet, physical activity, stress management, smoking cessation, and social support [96]. The ¡Viva Bien! intervention did not use technology, and cost of implementation was identified as a barrier to widespread dissemination [97]. For this reason we were interested in exploring use of Interactive Voice Recognition (IVR) telephone technology to deliver some aspects of the program, to potentially increase the adoptability of the intervention in primary care. To better understand how to improve cost-effectiveness and long-term engagement with diabetes self-management interventions, qualitative data were collected from a subset of participants that had completed the main study components to understand their satisfaction with specific program elements, what they thought about using different forms of technology to achieve their diabetes self-management goals, and their recommendations for changes and enhancements to future versions of the two interventions with regard to the integration of technology into their daily lives. For the qualitative components of MyPath and ¡Viva Bien! the sample composition and size were planned to assure that participants in interviews or focus groups represented the main sample of patients that participated in the clinical trials.

2.2 Measures

The present investigation draws on qualitative data generated from focus groups with selected MyPath participants and telephone interviews with selected ¡Viva Bien! participants. In MyPath, four focus groups were conducted to understand how to improve the website to maximize its impact on sustaining behavior change, two focus groups were held with people older than 65 years of age to explore relevance of various technologies as well as potential digital divide or computer literacy issues, and one group was conducted with people having poorer medication adherence to understand their special needs. In ¡Viva Bien! telephone interviews were conducted with a diverse group of participants to collect their thoughts on virtual vs. human support and to elicit their reactions to the idea of accessing components of the intervention via telephone. Focus group and interview topics are detailed in Table 1.

Table 1 Semi-structured telephone interview and focus group topics and items

Topic	Items	
	Telephone Interview Items	Focus Group Items
Interest in technologies to help with stress, diet, exercise, medication taking, or smoking	How comfortable would you feel getting pre-recorded phone calls from ¡Viva Bien! staff about helping with your stress, diet, exercise or smoking?	In general, what types of things would you look for in a web-based program? Is it important for a web-based program to target diabetes specifically? Do you think that you would use a virtual coach in your everyday life to help you with diabetes self-management?
Interest in technologies to connect with program staff or healthcare team	What if, when this phone system called, it let you check in with anyone you want from ¡Viva Bien! staff?	Do you think that you would use an “ask an expert” feature in your everyday life to help you with diabetes self-management?
Interest in technologies to connect with peers and others for social support	How much would you like it if the system let you check in with a buddy/another participant you know from the ¡Viva Bien! program?	Would you like to invite people to cooperate in goals/activities with social media? Do you think you would like to??? add people to your support group through social media? Would you like to publish your (diet, exercise, medication taking) accomplishments in this social media format? Would you like to read about other people’s achievements or success stories in this way? Would you like your supporters to see how you are doing with your diabetes though social media? Would you like to receive feedback from your supporters through social media?
Indication to use technologies	How much do you think you might use the check-in option? How much do you think you might use the buddy/peer support option?	Would you use this type of program? How often would you use this program?
Helpfulness of technologies	Overall, how helpful do you think a phone system like this would be to you?	What do you like about this program or feature? What do you dislike about this program or feature? Would a place to track your medications in addition to your food and exercise be helpful? Do you think this tool would help you remember to take your medications? What do you like about this tool in helping you remember to take you medications? Are you more/less likely to use a refill program in comparison to the reminder program? Do you think this tool would help you stay on top of medication refills? Would you prefer/not prefer to use a tool aiding in medication taking or simply have available information or resources for medication?
Recommendations for technologies	What, specifically, would make a phone system helpful for you?	How would you improve this program? If you wanted to access one of these program features through a phone, what features would you want included?
Design and features of technologies	N/A	What do you think about the design and layout?

Table 1 (continued)

Topic	Items	
	Telephone Interview Items	Focus Group Items
		What features would make you want to visit this site daily? What other features would encourage you to visit this site daily? Do you think you could easily find this tool? Do you think you could use all the features of the tool? Does the tool look simple enough to use? Too simple? Do you think it would be difficult to manage or use this program? Thinking about the computer you use most often, do you think your computer could access this site?

2.3 Focus group and interview procedures

The MyPath study was conducted from 2008–2011. Seven focus groups were conducted in 2011 at Kaiser Permanente Colorado clinical locations. The 90-minute sessions were led by research staff in English. Participants were asked to discuss their experiences with the project website, then were shown other online sites and asked to share their likes and dislikes of those sites as well as potential uses of site features and tools. Topics included diet, exercise, medication taking, social media, and different types of technology. The ¡Viva Bien! study was conducted from 2006–2010. Semi-structured telephone interviews by project staff were completed in 2010 with 18 ¡Viva Bien! participants. Interviews lasted about 60 min; 16 interviews were in English and two were in Spanish.

2.4 Data analyses

Notes and audiotapes from focus groups and interviews were transcribed and coded by research staff. First-cycle coding employed descriptive coding [98] by two individuals to analyze content and identify preliminary themes; coders then met to clarify and define data codes. Using the set definitions and inclusion/exclusion criteria, three coders completed second-cycle coding [98, 99] with 79.1% inter-coder agreement. Eighty percent of material was double coded to assure reliability. Codes and themes were discussed with research team members to hone definitions and assure consistency. As data were originally collected for purposes specific to each study, i.e., to understand participant satisfaction

with the specific programs and to solicit patient input into use of various forms and features of technology to support their diabetes self-management goals, content analyses and coding were initially performed separately for each dataset. The coded data were quantified [100] and condensed into major categories that emerged inductively from each dataset [98]. These categories were then merged to reorganize the content extracted from the two datasets in order to answer the more general research questions posed in this paper [101]. Preliminary findings were debriefed with the research team to confirm findings [102, 103].

3 Results

3.1 Participant characteristics

Participants were invited purposefully to assure demographic representation of those participating in the larger study, with regard to gender, age, race and ethnicity. All participants were adults with a diagnosis of type 2 diabetes and at least one other risk factor for heart disease (i.e., were obese or had poorly controlled A1c, Lipids, or blood pressure). Thirty MyPath intervention participants were selected to attend one to two focus groups ($N=7$ focus groups) with about six (range=5–12) attendees per group. For the ¡Viva Bien! interviews, nine women were selected from the control group and nine from the intervention group representing a range of adherence to intervention components. Participant characteristics are presented in Table 2.

Table 2 MyPath focus group and ¡Viva Bien! semi-structured interview participant characteristics

	Focus Groups (<i>N</i> =30) Mean (SD) or %	Phone Interviews (<i>N</i> =18) Mean (SD) or %
Gender (% female)	53.3%	100%
Age	58.9 (10.4)	59.5 (8.9)
Body mass index	36.1 (8.6)	35.3 (7.4)
Baseline smokers	20.0%	5.9%
Income		
< \$10,000 (¡Viva Bien! \$0–\$14,999)	0%	16.7%
\$10,000–\$29,999 (¡Viva Bien! \$15,000–\$29,999)	17.2%	27.8%
\$30,000–\$49,999	27.6%	27.8%
\$50,000–\$69,999	27.6%	5.6%
\$70,000–\$89,999	6.9%	5.6%
\$90,000+	20.7%	16.7%
Glucose-lowering medication		
Oral	63.3%	66.7%
Insulin	10.0%	11.1%
Insulin and oral	20.0%	11.1%
None	6.7%	11.1%
Level of education		
<High school graduate	3.3%	22.2%
High school graduate	16.7%	22.2%
Technical/some college	40.0%	27.8%
Completed college	40.0%	27.8%
Race		
American Indian/Alaska Native	10.0%	
Asian	0%	
Native Hawaii/Pacific Islander	0%	
Black or African American	10.0%	
White	73.3%	
Did not answer	6.7%	
Hispanic/Latino (% Latino)	13.8%	100%
Health literacy: 1 (low)—5 (high)	4.9 (0.3)	4.4 (0.8)
Numeracy: 1 (low)—6 (high)	4.3 (1.2)	3.8 (1.0)

There were no significant differences between MyPath or ¡Viva Bien! focus group/exit interview participants and main-study participants.

3.2 Answers to research questions

3.2.1 Using technologies to support diabetes self-management

Most of the 18 phone interviewees (*n*=13) said an interactive voice response (IVR)-type program would help them maintain a healthful lifestyle. Twelve said they would be either “a little comfortable” (*n*=4) or “very comfortable” (*n*=8) with such an automated system; only one interviewee said she would be “very uncomfortable”. When asked about getting pre-recorded phone messages to support their self-management, respondents felt that these should be tailored reminders that were specific to their goals. One commented that it would be helpful to have, “somebody to give me a little jab to get me going.” Four of the telephone interviewees also said they have

used the Internet to help with their diet, to find exercises, and for information on stress management. Focus group participants had more experience using the Internet than interview participants, but said they preferred websites with menus that allowed them to access a wide variety of information related to their diabetes self-care; and allowing them to find what they needed in one place. One commented, “I would like to choose from a pull-down list, this would be very useful, particularly with medications.” Another mentioned the desirability of having a single place to track everything. One said, “I track so many things, it’s nice that it’s all in one place.” Others stressed the need for information that was tailored to them, and suggested “smart” programs that “ask the right questions” and then recommend what they need. They also liked the idea of being able to customize their own page (e.g., iGoogle) so that information and tools were relevant. One said, “Yeah,

2000 calories is standard, but it would be important to be able to change it to what people need and want.”

3.2.2 Using technologies to connect with members of the healthcare team or program staff

Using technology to communicate with others was acceptable, but patients were less interested in one-way communication with automated support messages via phone, email, or text. In addition, all participants were supportive of technology that would allow them to report progress and receive coaching from members of their healthcare team or diabetes program staff. Focus group participants expressed a strong desire to share progress with their providers either electronically or via a computer printout. One said, “I would like my tracking journal to be hyperlinked to my medical chart.” Patients also liked the idea of being able to ask anonymous questions over the Internet and have continuous access to information through a website that allowed them to ask questions of a qualified person, as long as responses were prompt. Phone interviewees said it would be important to not just report progress using an IVR system, but also to receive feedback on their goals. They said they would welcome suggestions on how they could improve or meet goals, and would like to have their questions answered by experts, such as a dietitian. Some participants also said they would attend virtual Internet workshops with audio and visual features. When participants were asked about substituting virtual support for live support, such as a virtual expert or coach, participants were favorable so long as the virtual expert or coach knew something about them and provided tailored advice. Use of avatars or animated characters as buddies or coaches was generally favored as a way to make the program more fun and “social”; but most respondents preferred using technology to increase their access to knowledgeable human beings. Of the nine phone interviewees asked how much they would like to be able to talk to a ¡Viva Bien! program staff member or another participant after completing an automated IVR call that asked them about their self-management goal progress, two said they “might like” and six said they “would definitely like” that option. Interviewees commented that such a feature would help provide social support that was sometimes lacking in their lives. One said it is important to be accountable to a real person because “it’s easy to lie with pushing buttons.”

3.2.3 Using technologies to connect with social support networks

Focus group participants universally preferred in-person contact to social networking sites such as Facebook, saying in-person contact was “more engaging” and “interactive.” They also said they liked receiving advice from those with diabetes or from those who live healthful lifestyles,

not necessarily solely from experts. One said, “I’m not so interested in following skinny people who don’t have diabetes, but you can get really great information from healthy friends who have great tips.” Asked about an automated telephone system that could provide tips via voicemail or text, some phone interviewees stated a strong preference for human contact, saying, it is “really frustrating to use automation,” and, “there is nothing like a human voice.”

3.2.4 Improving the user-friendliness of health information technologies

“*Navigability* was the top issue for both focus group and telephone interviewees when it came to using technology. Phone interviewees were concerned about the technologic aspects of accessing information or responding to automated questions using their telephone keypad, such as navigating through a push-button system. One noted, “I get very confused.” Focus group participants were also concerned about navigating through complicated websites. Participants didn’t want to have to work to access information. One noted, “I do not like it when I have to scroll down the page to get the information. I would like information to be split up across pages.” Older participants said they would like technical support whenever they needed it. They agreed that a simple list of sequential steps to set up the main features of the program could be useful, but they wanted instructions. One said, “I would want help to create the page, and then get suggestions or ideas on what to add.” *Readability* was also emphasized by focus group participants. Most expressed a preference for interfaces that were clean, clear of advertisements, and in an easy-to-read typeface. For participants older than age 65, contrasting color including use of dark print on light backgrounds, and the ability to choose colors, font size, and other design elements were important features. Patients also wanted to choose their own passwords, if required, rather than having one assigned to them, so they could easily remember it, versus having to find where they wrote it down. *Cost* was also raised as a potential issue, particularly with using cell phones. Participants agreed that diabetes self-management programs and tools should be easily accessed through multiple platforms (i.e., cellphones, smartphones and computers) but must also be free of charge. One said, “Some of us have unlimited text plans and others may pay per text, so it is important to set up reminders that I wouldn’t be charged for.”

3.2.5 Using Internet-based resources to manage specific health behaviors (focus groups only)

Healthful eating Patients differed on the specific Internet food resources they preferred, but agreed that they desired choice, the ability to customize, and receive practical and

timely information. Some favored food diaries and the ability to track nutritional factors and some wanted guidance on meal planning. Participants said they would like recipe searches and meal planning based on specific criteria (e.g., carbohydrates, sodium, calories; vegetarian, kosher, Indian; under 200 calories, under 15 carbohydrates). Patients also were interested in mobile technology applications to track their eating “on the go” and to find restaurants that meet their nutritional criteria and preferences.

Exercise Patients wanted a program to help them set exercise goals, track exercise, and receive tailored feedback. They said it would be helpful to include all lifestyle activity, not solely exercise. One said, “I garden and do housework, not fitness. I tried the treadmill, and it’s not my thing. Gardening is what I like to do.” Patients also wanted to review their weekly, monthly and annual progress. One said, “It gives you some perspective as to where you are at, and you can reward yourself.” Some patients desired downloadable graphs and charts to illustrate their progress. They also asked for feedback on caloric intake, calories burned, calories remaining after exercising, and glucose readings. They were less interested in general exercise information.

Medication Unlike exercise, patients most wanted to use e-technology to access information. Suggestions included pull-down menus with diabetes medications that included timing, dosage, and food consumption instructions, plus information on side effects. One said, “How does my diabetic medicine go with this cancer medication you gave me? That is pretty important.” Participants wanted the program to allow them to request refills, and to receive reminders to take medications or to order refills. They also wanted the program to be tailored and linked to their providers. One noted, “If it was on the (provider) website, you could email a message to your doctor and set up the reminders.”

Social media Patients clearly appreciated the potential of social media to help them interact with peers, receive motivation and tips, and make friends. One said, “I’m very social. This would be a place where I can say, hey, I’m walking at so-and-so at this time. Want to join?” But they were concerned about keeping personal information private. One said, “I am a high school teacher. I worry about my students having access to my profile.”

4 Conclusions

This paper summarizes recent literature and presents qualitative results from two studies to document patient preferences with regard to using web-based or phone-based tools

for supporting their diabetes self-management goals. The study data were generally consistent with the literature [21], indicating patient agreement that technology would encourage them to attend to their health-behavior goals, and would be useful as a tool to track progress [54] and receive helpful information at any time [58].

Results indicate that, while individual diabetes patients differ on how they use technology for behavioral support, they agree that they want choice. Also, the features they desire from an e-health application differ for different health behaviors. That is, patients favor a range of tracking tools and “just-in-time” information to support healthful eating, but for physical activity they prefer feedback on their energy balance and for medications they mostly want an easy way to look up information and receive refills.

The study underscores the importance of two-way communication and human contact. Participants clearly want e-health technology to help facilitate exchanges with their healthcare providers, program staff, and peers, and they are less interested in virtual health coaches or public online social networks.

This study also suggests that Internet and mobile technologies can improve access to diabetes self-management programs. Most of the ethnically and socioeconomically diverse participants said they would use technology to support their diabetes self-care. To reduce barriers, though, such programs should be free or low in cost and easy to use, with personalized instructions and technical support.

A limitation of this study is that focus group participants and interviewees may have had preconceived ideas based on their experiences with either the online MyPath program or the in-person ¡Viva Bien! program. In addition, since ¡Viva Bien! was a program for Latina women, both Latino men and non-Latinos were not interviewed, limiting generalizability. In addition, all participants received healthcare from a large HMO in an urban/suburban setting, so are not representative of patients who are uninsured, or residing in rural areas. Strengths include a patient-centered approach and samples that were representative of participants in the two large diabetes trials from which they were drawn; and included a diverse mix of ages, genders, ethnicity, education and income levels. Participants in this study provided a useful perspective and a surprising amount of agreement on preferences for choice of technology and features, for programs that are timely and personalized, and for programs that do not replace humans but rather facilitate accountability to and communication with others.

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