

Feasibility and Use of an Internet Support Service for Diabetes Self-Management

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Diabetes self-management is a challenging task due to its complexity and ever-present barriers to self-care. A key issue for patients, providers, and healthcare systems is how to deliver personalized behavioral support in ways that are affordable and can reach most patients. The Internet offers several advantages in this regard because it is available 24 hours a day, low cost, and capable of reaching thousands of patients. Although Internet sites for diabetes support are popular, they have not been evaluated. For this study, a Web site for diabetes self-management that emphasized personalized goal setting, feedback, and social support was developed. Over a 10-week period, 111 different persons logged onto D-NET for a total of 21 046 accesses. Users included persons across a broad age range (up to age 77 years) and duration of diabetes. The most popular areas of the site were the Social Support Conference and the Diabetes Information Pages. User ratings revealed high satisfaction with the service. The Internet has great potential for providing needed support and services for patients with diabetes and other chronic illnesses.

There is a need for innovative and validated low-cost interventions to facilitate lifestyle changes among persons with chronic diseases.^{1,2} This is especially true for persons with diabetes, which is associated with increased morbidity, mortality, and medical costs.^{3,4} The diabetes self-management regimen is one of the most complex and challenging regimens for any chronic disease and requires a high level of patient involvement.^{5,6} The Diabetes Control and Complications Trial⁷ conclusively demonstrated that tighter control of blood glucose levels dramatically reduces diabetes complications. The major current challenge is how to deliver the necessary skills training and support to diabetes patients that will allow them to control their blood glucose and other risk factors in ways that are cost effective. One of the reasons for the success of the DCCT was quite likely the amount of support, contact with healthcare professionals, and attention provided.⁸ However, the amount of direct and telephone contact provided in the DCCT is unlikely to be feasible in most practice settings.

The purpose of this paper is to explore the feasibility of an Internet-based diabetes self-management and support program. There are three major limitations to most current approaches to diabetes education: (1) the cost and the amount of time required of both patients and professionals; (2) the limited reach and availability of programs for persons who work, live in rural areas, or do not want or cannot afford participation in group education sessions^{9,10}; and (3) the ongoing support required for long-term maintenance of behavior change.¹¹⁻¹³ Each of these limitations can be addressed via an Internet Web site.

Computer-mediated health education and support (CMHES) offers several advantages. Patients can access educational and support resources from the privacy of their own homes. This support is available 24 hours a day at times when patients are most in need of and ready to use self-management information. Electronic entry and scoring of assessment information can provide rapid, personalized feedback and recommendations for self-management. Equally important is the high degree of ongoing support that can be provided through options such as chat rooms,

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conferences, and related Internet services for sharing among patients. A variety of diabetes home pages have been created,¹⁴ and the number of people with Internet access is growing exponentially.¹⁵

There are also potential limitations to CMHES services. These concerns include the feasibility and cost of establishing and maintaining a high quality service; restrictions of availability to patients who are wealthy, highly educated, and computer savvy; and the potential for transmission of misinformation or advice via the group support aspects that could be harmful to patients. A review¹⁴ of existing diabetes Internet services suggests that such sites focus primarily on knowledge-based information¹⁶ or on providing peer social support, but have not integrated a personalized self-management training approach with support, and have not evaluated the services.

The development and initial use of an Internet-based CMHES system for diabetes self-management is described in this article. The system, user characteristics, patterns of use, and user satisfaction are presented, and recommendations are made for future use of such systems to support self-management of diabetes and other chronic diseases.

Methods

The Diabetes Network (D-NET) World Wide Web site was launched on June 19, 1996. Data were collected over a 10-week period until August 30, 1996. Due to cost constraints, only current Internet users who were adults with either type 1 or type 2 diabetes were included in this pilot research. Participants were recruited via e-mail letters sent to existing diabetes Internet news groups and listservers (group mailing lists).

Development of the Service Based upon previous success with a brief physician office-based, touch-screen computer-assisted intervention¹⁷ to improve diabetes self-management and dietary patterns, an extension to the Internet was developed. Participants had access to D-NET via their own computer, software, and Internet provider. There were "pages" of information (eg, documents), a library of 996 recipes, and a confidential, personal database manager from which participants could track their home glucose monitoring in a graphic feedback form.

There were three major components to the D-NET pilot system. The Information component provided a large number of diabetes-specific articles and was divided into five sections: medical information, healthy eating, healthy lifestyles, managing your diabetes, and the reading room. The Social Support Group component provided participants with an opportunity to exchange diabetes-related information, coping strategies, and emotional support. The Personalized Blood Glucose Monitoring component provided participants with a personalized database in which they could enter their daily blood glucose monitoring information and receive graphic feedback. This component required Web browsers that were newer and Java capable.

Recruitment Procedures The following inclusion criteria were established: persons with a self-reported diagnosis of either type 1 or type 2 diabetes; persons with access to a computer, software, and connection to the World Wide Web

(WWW); and able to read and write English. When respondents to the e-mail recruitment letter first connected to D-NET on-line, they received an informed consent form that described the study approved by the Institutional Review Board for human subjects. Participants then completed on-line assessment questionnaires that were used to gather information about demographics, diabetes self-management patterns, and computer experience. Once these initial measures were completed, participants accessed the D-NET Web site using a name and password of their choosing. All information was automatically recorded in the database for the project. Participants automatically received an e-mail message welcoming them into the project and reminding them of their logon name and password. Participants were able to access D-NET 24 hours a day.

Measures Process measures (on-line assessment questionnaires) were used to collect data on the following variables: demographics, medical history, computer use, and Internet experience.

Demographic data included gender, age, educational level, employment status, race, and ethnicity. Medical history data included duration of diabetes, number and type of other chronic diseases, and current diabetes medication status (no medications, oral agents, insulin, or a combination of both). Data concerning computer experience included whether participants owned a home computer and the number of years of Internet use. Automated on-line assessment of participation provided information about use of various components of the network and user satisfaction. Information about Web site usage also was collected to describe the extent of use and appeal of the intervention delivery system. Web site activity logs were developed that tracked and provided descriptive information about (1) the time of day at logon; (2) the length of time on the Web site; (3) the number of times logged on per week; and (4) the length of time spent in the Information, Support Group, and Personalized Self-Management areas of the Web site. For the Support Group component, information also was collected concerning the number of messages read, the number of messages written, and the number of words per message.

An on-line user satisfaction survey was completed by 70 of the 111 participants. This survey assessed the ease of use of D-NET and the helpfulness of the diabetes information provided, the diabetes social support group, and the personal blood glucose monitoring feature with graphic feedback components.

Results

Despite the relatively brief and low-intensity recruitment procedures, a total of 111 different users logged onto the D-NET home page. Given that the sample was restricted to persons currently having Internet connections, the diversity of types of users was surprising (Table 1). The median age was 43 years, the oldest user was 77 years old, and 9 participants were over 60 years old. Thirty-four percent of the users were female, and most had had diabetes for a number of years (mean=9.2 years). Users came from all over the world including the Czech Republic, Norway, Netherlands, Canada, UK, Mexico, Slovenia, Portugal, and Australia. The majority of user sessions (83%) were from the US, with Hawaii, Florida, and Virginia having the greatest number of sessions.

Table 1. User Demographic and Medical History Characteristics, n=111

Characteristic	Mean (SD) Range	Percent of Users
Age, y	43.4 (12.5) 7 to 77	
Gender		
Male		65.8
Female		34.2
Educational level, y		
0 to some high school		1.8
High school graduate		5.4
Some college		29.7
College or university		37.8
Graduate degree		25.2
Employment		
Full-time		65.8
Retired		7.2
Disabled		7.2
Other		19.8
Medical History Variables		
Type of Diabetes		
Type 1		31.9
Type 2		68.1
Years Diagnosed		
<1 year		18.9
>1 year		81.1
Diabetes medication status		
Taking insulin		59.5
Not taking insulin		40.5
Comorbidity		
No other chronic disease		42.3
1 to 2 other chronic diseases		36.9
≥3 other chronic diseases		20.7

The sample was highly educated, with 63% having completed college. Two thirds of the users were employed, eight were retired, and eight were disabled. In terms of diabetes characteristics, 68% had type 1 diabetes, 60% were on insulin, 28% were on oral medications, and 12% were not prescribed diabetes medication. Fifty-seven percent had at least one other chronic disease, and 21% reported three or more chronic diseases in addition to diabetes. The sample, therefore, was relatively heterogeneous although highly educated. An encouraging finding was the number of older persons using the system, including those with other chronic conditions and disabilities.

As would be expected given the recruitment procedures, this group of participants had computer experience. Eighty-two percent reported that they were very familiar to extremely familiar with computers, 82% had been using computers for at least 5 years, and 99% stated they were comfortable using computers. The mean time that users reported using the Internet was 2 years; 51% reported using the Internet for 1 year or less. Participants also used a variety of components of the Internet to help them manage their diabetes, such as diabetes-specific news groups and listservers, chat

groups, bulletin board services, commercial services (eg, CompuServe, America Online, etc), and the World Wide Web. All participants used at least one of these components of the Internet and 70% reported using two or more of these components to assist them in managing their diabetes. Most participants used D-NET from home (80%), with the remaining users accessing it from work or school.

User Characteristics of Postassessment Survey Completers vs Nonrespondents The 70 users who had returned the D-NET satisfaction surveys (completers) as of this writing were representative of the larger sample of 111 persons who participated in this study. The median age of postassessment completers was 43 years, with the oldest being 75 years. Forty percent were female, and this subsample was highly educated with over 50% having completed college. Over half of the completers were employed. Fifty-eight percent had been on the Internet for 1 year or less. In terms of diabetes characteristics, 72% had type 2 diabetes, 55% were on insulin, and 24% reported three or more chronic diseases in addition to diabetes. Comparisons of the postassessment completers with the nonrespondents revealed that the two

Table 2. Summary of Helpfulness Ratings for D-NET Components by Length of Illness

D-NET Component	Recently Diagnosed (1 to 24 months)	Living With Diabetes (>24 months)
	n (%)	n (%)
Information	35 (98)	32 (90)
Social Support		
Posters	8 (75)	8 (100)
Lurkers	18 (88)	17 (94)
Composite	8 (87)	8 (100)
Personal Blood Glucose Monitoring	18 (73)	11 (100)

groups were highly similar in terms of demographics, medical history, computer use, and Internet experience; there were no significant differences on any of the variables (Table 1).

Usability and Satisfaction With the Service Usability is an important determinant of the effectiveness of any CMHES service. There are two issues associated with usability: availability (Is the service available to users at their own convenience?) and access (How easy is it to use?).

The usability of D-NET was assessed in two ways. First, availability was assessed via analysis of the Web site log file. This record revealed 1969 "hits" or visits to the home page and 21 046 total hits during the average of 7 weeks that participants were involved in the study. There was an average of 12 user sessions and 366 hits daily, and use throughout the day included early in the morning and late at night by participants at home (74%) and work (24%). A similar level of use during the weekend (average of 13 user sessions and 373 hits per user session) suggests that participants took advantage of the 24-hour, seven-day-a-week availability of D-NET to support their diabetes self-care efforts.

The second way in which the usability of D-NET was assessed was via the postassessment survey. Participants were asked, "How would you rate D-NET on ease of use?" Using a 6-point scale with ratings from Very Easy to Very Difficult, 94% rated D-NET as easy to use and stated that they would recommend D-NET to family members or friends with diabetes. Gender, age, and length of time on the Internet were not related to ratings on these items.

Evaluation of D-NET Components *Diabetes Information Component* According to the D-NET Web site activity log, the diabetes information component was the second most frequently accessed component, accounting for 36% of the activity on D-NET. The rank-order of the sections in terms of frequency of use were the D-NET magazine, Medical Information, Managing Your Diabetes, Healthy Eating, and Healthy Lifestyles sections. Because the frequency of access to these pages did not provide a direct answer regarding how helpful the information was to participants, a satisfaction item was included in the postassessment survey. Participants were asked to respond to the following question using a 4-point scale with ratings from Very Helpful to Not At All: "Did you find the information sections (eg, Healthy Lifestyles, Healthy Eating, Medical Information, etc) helpful in managing your diabetes?" Ninety-five percent of

respondents reported that the Medical Information section was helpful in managing their diabetes.

Social Support Group (SSG) Component This feature was the most used component of the Web site; the SSG accounted for 60% of the activity on D-NET. The activity log revealed a total of 964 hits among 249 distinct user sessions of this feature. Over 120 messages were posted, and there was evidence of many "lurkers" (users who read but do not post messages). Participants were asked two questions on the postassessment survey about the helpfulness of the SSG, one relating to message posters and the other to lurkers. Among those who used this feature, 89% reported that posting messages in the SSG area was helpful in managing their diabetes. Lurker participants were asked, "If you read but did not post messages in the Diabetes Social Support Group Area, did you find it helpful in managing your diabetes?" Ninety-three percent reported that they found merely reading messages from other participants helpful in their self-care efforts.

Personal Blood Glucose Monitoring This technically sophisticated component that enabled users to create, modify, update, and generate real-time graphic feedback on their blood glucose levels at various times of day was the least used component. Unfortunately, this component required the latest versions of Netscape® or Microsoft® Internet Explorer with the more advanced features needed to generate real-time graphs based on user input. The limited number of participants (43%) who had browsers capable of displaying dynamically created graphs and were able to explore this option were asked on the postassessment questionnaire whether they found this feature helpful; 84% indicated that it was helpful in managing their diabetes.

Differential Ratings on D-NET Components A strength of CMHES services is the wide variety of choices or services from which participants may choose as their needs change. For example, the needs of a person newly diagnosed with diabetes are different than the needs of someone who has lived with the illness for many years. To demonstrate this difference, the postassessment responders were divided into two groups, newly diagnosed participants (those in the first 24 months after diagnoses) and those diagnosed with diabetes for more than 24 months. A comparison of differential D-NET component ratings by disease duration is illustrated in Table 2.

This table reveals a pattern of differential ratings of "helpfulness in managing my diabetes" across components of D-NET as a function of where participants were in the course of their illness. Those more recently diagnosed rated the Information component more highly (98%) than those living with diabetes for 2 years or more (90%). In contrast, those with a longer duration of diabetes rated both the Social Support components (100%, 94%) and the Personalized Blood Glucose Monitoring component (100%) higher than those with a more recent diagnosis (75%, 88%, and 73%, respectively). This information is presented merely as an illustration (tests of significance were not conducted due to the small sample size), although the findings generate a hypothesis that could be rigorously tested in a controlled clinical trial.

Discussion

The D-NET appears to be a feasible and stable CMHES system. The home page was established and maintained for 10 weeks using relatively widely available hardware and software. The current interface was designed to permit ease of use and was rated by 94% of participants as easy to use. The current costs of a home computer, modem, and software to access the D-NET system are estimated at approximately \$1000. The percentage of families that have Internet access is increasing exponentially, and it is estimated that the costs of an Internet "box" will drop substantially with the wide-scale introduction of Internet appliances.

Despite a relatively brief and low-intensity enrollment period, 111 different users accessed the D-NET home page. Because the study was limited to those currently having Internet access, the reactions of novice users to the system could not be assessed. However, the range of users and especially the substantial percentage of females, older users, and those having been on Internet for a year or less were encouraging. These data suggest that the system may have relatively broad appeal, including those with other chronic diseases and a variety of diabetes regimens. Participants in this study were highly educated, however, and relatively experienced computer users. Future evaluations with less educated and more novice computer users would be helpful for evaluating the dissemination potential of such systems.

The current system was perceived as helpful as indicated by both the continuing pattern of use over time and by user satisfaction ratings. The most frequently used area of the CMHES system was the Social Support Group. The results concerning this component of D-NET are encouraging given the relatively short period of time in this study for the on-line support group to coalesce. The frequency of use and popularity of the Social Support Group indicate that this component is worthy of more detailed evaluation. Continuous monitoring of the information exchanged and issues discussed by patients using the social support features indicated that the most common uses were for information and emotional support. No instances of sharing inappropriate advice were observed. A pattern frequently seen with chat rooms and BBSs in which those who do not actively participate but lurk or read the messages being exchanged and find the interaction beneficial¹⁸ also was observed in the Social Support Group.

Several criteria that were used in the development of the D-NET pilot project can serve as a guide for developing

similar interactive Web sites. First, the site should be relatively easy to set up, cost effective to maintain, and easy to use for people of all ages and levels of computer experience. Second, such a Web site should be highly interactive yet shield the user from complications of use and the need for technical knowledge. The hardware and software used for D-NET were selected with these criteria in mind. The data presented in Table 1 illustrate an advantage of using Web-Trends log analyzer for CMHES interventions, namely the automatic collection and display of user and implementation statistics that help to document and reveal how such an intervention works.

Some participants encountered technical difficulties involving the use of frames and Java. Frames are a design technology that allow easier navigation of a Web site and avoid the problem of users becoming lost in a labyrinth of web pages, a common complaint among novice users. The advanced features of the latest Netscape and Microsoft Internet Explorer Web browsers, which are Java capable, were used to display the real-time graphics for the blood glucose monitoring component of D-NET. The inclusion of Java in Web pages has many applications that could be implemented in future versions of D-NET to make it more interactive, user friendly, and attractive.

However, both frames and Java require browsers that are capable of handling these newer technologies. Consequently, some participants using older Web browsers encountered difficulty in navigating on D-NET, using the real-time graphing capabilities, or had difficulty logging on. These particular features should not be a problem for future use. However, the generic issue of striking a balance between use of the optimal, cutting-edge technologies and at the same time making a Web site available to the largest number of users will always be present.

This pilot project had several limitations despite the optimistic potential of D-NET and similar CMHES systems. The impact of the intervention on self-management outcomes was not evaluated; only use and user satisfaction (necessary but not sufficient criteria) were assessed. The D-NET program was not intended to replace conventional diabetes education but to supplement usual care for existing patients who often receive little self-management support.^{19,20} Because of financial constraints, eligibility was restricted to those who were existing computer users. Future research should investigate the use and acceptance of the system by novice and particularly older patients with chronic disease. Finally, although the Social Support Group component appeared popular and helpful, its incremental impact on outcomes and cost-effectiveness beyond that of the basic Web site should be studied in future research. In conclusion, this report documents the establishment, feasibility, and usefulness of a diabetes CMHES system. The goal is to make refinements in the system and evaluate its potential for dissemination in future research.

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