

# Activating chronic kidney disease patients and family members through the Internet to promote integration of care

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## Abstract

**Purpose:** To describe the potential role of the Internet as a vehicle for improving integration of care through activating chronic kidney disease patients and their family members. Also, to describe how that potential is being developed through a website sponsored by the Medicare program in the United States.

**Background:** The Internet is expanding at a rapid rate, and health-related websites are one of its most popular features. Efforts to promote integration of care have focused mainly on providers up to now, and more emphasis is needed on the potential roles of patients. Chronically ill patients have particular needs for improved education about their conditions and enhanced involvement in care planning and treatment decisions. Medicare developed the Dialysis Facility Compare website to serve those goals for people with chronic kidney disease.

**Methods:** We conducted qualitative research with 140 chronic kidney disease patients and family members, and 130 renal care professionals to evaluate and improve the Dialysis Facility Compare website. A series of 19 focus groups, 13 triads (small focus groups), and 56 individual interviews were conducted in four regions of the United States and by telephone.

**Results:** We found that the Dialysis Facility Compare website has the potential to improve integration of care for people with chronic kidney disease in at least three ways. First: by expanding the roles of patients as members of the multi-disciplinary team of caregivers treating their disease. Second: through better integration of the informal care provided in the home and community with the formal care provided by health professionals. Third: by improving coordination of between care provided in the pre-dialysis and dialysis phases of the disease.

**Discussion:** We developed recommendations for revising and enhancing the Dialysis Facility Compare website in a number of ways to better promote patient activation and integration of care. The unique features of the Internet, such as its different dimensions of interactivity, and applications of behavioural theories for website design should also be further explored.

## Keywords

**integrated care, client perspective, chronic care, the internet, disease management, chronic kidney disease**

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The Internet shows great promise as a vehicle for activating patients and improving integration of care. Websites can provide access to a wide range of health care information and educational programs and enable them to be tailored to the needs and interests of individual patients and their family members. Such access can enable patients to become more active in managing their own care and better partners with their doctors and other caregivers.

While still a relatively new technology, access to the Internet has expanded at a rapid rate. The Pew Internet Project reported that in December 2000, 56% of adults in the United States had in-home Internet access, about double the rate from just 3 years previously. Many people are also accessing the Internet through public libraries. A recent study in the United States showed that within a year after Internet-connected computers are placed in libraries, visits rise by 30% and are maintained at that level [1]. It has been estimated that the United States will have 211 million Internet users by 2006 [2].

Health-related applications have become one of the Internet's most popular features. Owen, Fotheringham, and Marcus estimated that each month more than half of all Internet users in the United States access health-related information [3]. Another study indicated that the number of adults who use the Internet for health-related information increased from 60 million in 1999 to 97 million in 2001 [4]. Moreover, 70% of online health care users agreed in a recent survey that the Internet empowers them to make better choices [2].

New health care websites are being developed at a rapid pace. Notably, a review of *The Patient's Internet Handbook* in 2003 commented that the book was important, but already out of date, despite being published in 2001 [5]. However, as Vass recently noted, there are currently many more websites available for doctors who wish to improve their communication with patients than websites designed to help patients narrow the communication gap between themselves and their doctors [6].

The Internet has a number of advantages over other media for health communications [3]. The Internet's interactive and hyperlink capabilities mean that groups and individuals can find information pertinent to their particular needs and interests, rather than a single generic version for all recipients. Moreover, users can access information at a time of their convenience, rather than being restricted to a point in time, as with television or radio. Users can also access Internet information as frequently as they wish.

The Internet shows particular promise for patients suffering from chronic diseases; they have time to build their knowledge and expertise in methods for managing their diseases, due to the long-term nature of their conditions. In the future, chronic disease patients could be provided personal web pages that are tailored to their individual medical conditions, risk factors, and interests [2].

This paper reports on qualitative research we conducted on the Dialysis Facility Compare website, focusing on issues related to integration of care. This website is sponsored by the Centers for Medicare and Medicaid Services, the agency that runs the Medicare program in the United States, for use by chronic kidney disease patients and their family members. It is intended to promote broader roles for patients in understanding and managing their own care, increase their participation in care planning and treatment decisions—such as choosing a dialysis provider—and to improve collaboration between patients and the range of health professionals providing treatment. It includes dialysis facility-specific data on the quality of dialysis care, facility services and characteristics, and educational information on kidney disease and dialysis treatment for patients and family members. It is available on the Internet through [www.medicare.gov](http://www.medicare.gov). An initial version of the Dialysis Facility Compare website was launched in 2001 [7]. Our study evaluated the extent to which it was achieving its goals; we also recommended ways to enhance it to better promote expanded roles for patients and family members.

To provide context, the following section of this paper reviews the nature of chronic kidney disease and dialysis treatment. We then discuss patient issues in integrated care, focusing on chronic disease. We next present the methods and results of our study. We conclude with a discussion of our recommendations for the website, the implications of our study, and possible directions for future research and development efforts on Internet applications to promote broader involvement of patients in integration of care.

## **Chronic kidney disease**

Chronic kidney disease has two main stages. The second stage is much more serious; it occurs when most or all kidney function has been lost. At that point, death will occur within a few weeks without dialysis or a kidney transplant. The second stage is often called kidney failure or end-stage renal disease (ESRD).

In the first stage, often called pre-ESRD or pre-dialysis, the patient retains enough kidney function to sustain life, but the function steadily declines over a

number of months or years. Patients are typically asymptomatic during that stage, and may be unaware that they have the disease. This is a serious concern, since a number of clinical interventions have been identified for that stage that can slow progression of the disease and prevent future complications and comorbidities [8].

The three treatment choices available to people with kidney failure are hemodialysis, peritoneal dialysis, and kidney transplantation. Hemodialysis involves using a machine to clean and filter the blood in order to temporarily rid the body of harmful wastes and fluids. It is generally performed in a dialysis facility, 3 days per week. Peritoneal dialysis also removes extra fluids and waste from the body, but it uses the lining of the abdomen to filter the blood. It involves patients themselves filling the peritoneal cavity in their abdomens with dialysis fluid several times per day and then draining it out several hours later. Kidney transplantation is usually the preferred treatment, but a lack of donor organs means that most kidney failure patients are on dialysis.

Unfortunately, the prevalence of kidney failure has been rising in the United States for many years. In 2001 there were over 406,000 kidney failure patients in the United States, an increase of 4.8% over 2000 [9]. In addition, about 8 million people were believed to have chronic kidney disease that would probably progress to kidney failure over time, unless death occurred earlier due to other causes [9]. Moreover, the numbers of kidney disease patients are expected to continue increasing, since they are associated with population aging and increasing rates of the most common underlying causes of chronic kidney disease, diabetes and hypertension.

Kidney failure is a very costly disease, and the costs have been rising for many years. Medicare expenditures for kidney failure patients were \$15.4 billion in 2001, 6.4% of the Medicare budget [9]. This was an 11.5% increase over the previous year. Kidney failure also causes heavy burdens of morbidity and mortality. Most patients suffer from multiple comorbidities, including diabetes, hypertension, cardiac disease, and depression. Mortality is high, with only about 33% of any given cohort of new dialysis patients surviving 5 years [9].

The severity of this disease, and the comorbidities frequently suffered by patients, make integration of care a vital issue. As the Institute of Medicine has noted, the health care system in the United States continues to focus primarily on acute episodes of care, while Americans are suffering from increased prevalence of chronic diseases, including chronic kidney

disease [10]. Treatment of chronic kidney disease is often fragmented in the United States, and patients often adopt a passive role. Lack of coordination and integration of care across providers, across sites of care, and over time has led to concerns about both quality and cost.

## Patient issues in integrated care for chronic diseases

Patient activation or empowerment has been shown to be an important element in improving chronic disease care. It includes both improving the patient's capability for self-management and increasing the degree of collaboration achieved between patients and their doctors and other providers. For example, Von Korff and colleagues reviewed studies on interventions to improve patient and provider collaboration in diabetes and Parkinson's disease. They found that both clinical and psychosocial outcomes were significantly improved [11]. Another study found that a patient self-management intervention improved some patient reported outcomes even in patients with milder asthma, where room for improvement in outcomes was limited [12].

In recent years, Internet-based interventions have been developed to promote patient activation. Several studies have found them to provide unique benefits. Ralston and colleagues reported that patients found value in an Internet-based diabetes disease management program that included enhanced e-mail communications with providers, educational resources, and interactive feedback on self-management activities [13]. Patients especially valued the support the program provided for their day-to-day management of the disease, the type of ongoing support not available through the more traditional acute office visits or phone calls to providers often too busy to talk. Glasgow and colleagues studied a range of Internet-based patient interventions in diabetes, including enhanced access to information, self-management training, and peer support [14]. They found improvement across a range of biological, behavioral, and psychosocial outcomes. Another study tested an Internet-based multimedia asthma education program, comparing it with traditional printed educational materials and verbal training [15]. The results showed that the Internet program provided a range of benefits to patients over and above the traditional approach, including improved asthma knowledge and lower clinical burden of illness.

Activating patients may be especially important for severe chronic diseases such as kidney failure, since many factors that affect patient outcomes occur out-

side the formal medical care system. patients' daily decisions regarding self-management include adherence to prescribed drugs, diet modifications and fluid limits, and making the effort required to attend every dialysis treatment. Just keeping track of patients' multiple medications presents a formidable challenge. People with kidney failure are often prescribed as many as 8–16 different medications [16, 17]. A recent qualitative research study found that long-term survivors of dialysis are active, comprehensive self-managers of their kidney disease and its treatment [18]. Of 18 long-term survivors studied, 17 had received extensive patient education and training.

Efforts to promote integration of care for patients with particular chronic diseases, including kidney disease, are often termed 'disease management.' These programs generally employ a combination of supply-side and demand-side interventions. For example, Wagner and colleagues identified five key elements: (1) the use of evidence-based, planned care; (2) reorganization of practice systems and provider roles; (3) improved patient self-management support; (4) increased access to expertise; and (5) greater availability of clinical information [19]. Disease management has been successfully applied to patients with other chronic diseases, and is now being offered to patients with kidney failure [20].

Early studies indicate that disease management has promise for improving kidney failure patient outcomes. In 1996, Medicare implemented an ESRD Managed Care Demonstration [21]. One of the sites was Southern California Kaiser Permanente, an organization known for its long commitment to kidney disease management [8]. Kaiser includes pre-dialysis patient education and dialysis self-management training as major elements in its program. In addition, on the supply side Kaiser is one of the most highly integrated delivery systems in the United States [22]. The Kaiser site was found to have lower mortality among its enrollees in the ESRD Managed Care Demonstration [21].

However, access to patient education materials and information and data to support self-management efforts have often been limited for those suffering from chronic kidney disease. Managed care organizations typically focus disease management programs on more prevalent diseases, such as congestive heart failure and diabetes. At the same time, most people with kidney failure in the United States remain in the fee-for-service system where patient education and disease management efforts may be limited due to

lack of staff time or limited knowledge of available patient education resources. The Internet represents a promising way to expand access to those resources for patients and their families. It can also help to improve communication and coordination between physicians and patients and their family members, which is also critical for ensuring that patients receive the appropriate care across all settings [23].

Several recent reviews have stressed the importance of patient empowerment in a comprehensive integrated care strategy [24–26]. However, the specific roles that patients and family members can take on to promote integrated care often need more detailed description. Those roles may sometimes be relatively limited, such as expressing preferences, involvement in some aspects of care planning, or involvement in specific treatment decisions. A more comprehensive view is that patients and their families should be encouraged to take on broader roles as self-managers of their own care and more active partners with physicians and other providers. Broader roles may enable more significant integration of care to be achieved. The Internet is one vehicle that can aid patients in taking on these roles. As Slack recently commented:

Patients make medical decisions for themselves all the time; sometimes the most difficult one is whether to go to the doctor. The goal is to have the interactive computer help patients make health care decisions in an enlightened and knowledgeable manner [28].

## Methods

We conducted qualitative research on the Dialysis Facility Compare website with dialysis and pre-dialysis patients, family members, and professionals. We focused on studying how this website can be effective in expanding the roles of patients and family members, including ways that promote integration of care. Professionals were included in our study since they routinely assist patients in making care and treatment decisions and often act as information intermediaries for them. We had four general objectives, to:

- Gain feedback on current Dialysis Facility Compare content and features from patients, family members, and professionals;
- Investigate current patterns of Dialysis Facility Compare use;
- Study the information needs of potential Dialysis Facility Compare users; and
- Identify ways to improve the Dialysis Facility Compare website.

**Table 1.** Study participants by type

Participant type	Number
Dialysis patients and family members	98
Dialysis professionals and technicians	98
Pre-dialysis patients and family members	42
Pre-dialysis professionals	8
Senior staff of dialysis chains, managed care organizations, and disease management organizations	18
Senior staff of national dialysis stakeholder organizations	6
Total	270

This paper focuses on the aspects of that research that relate to integrated care. We selected qualitative methods for this study since our research objectives included mainly subjective and exploratory issues on a topic (the website) with which most respondents had little or no experience. Qualitative methods provide opportunities for interaction between respondents—and between respondents and researchers—that can illuminate the range of reactions to a topic and the reasoning behind respondents' viewpoints or opinions. They enabled us to better understand the context and intentions from which participants' responses and ways of understanding and utilizing website information are generated. They also enabled us to explore new possibilities for this website, such as new types of information that could be added and would be useful for patients and family members.

During the period from December 2002 through May 2003, we conducted four data collection site visits, of approximately 1 week each, in four cities in different regions of the United States (Washington, D.C., Atlanta, Chicago, and Phoenix). Data collection methods included focus groups, triads (small focus groups), and individual interviews. Subjects were recruited through staff of local dialysis facilities, who contacted patients and family members and asked them to volunteer for the study. Staff then forwarded the names of the volunteers to us, and we screened them by telephone to obtain a mix of demographic and treatment characteristics among those selected for the study. Professional subjects were also volunteers from local dialysis facilities. We contacted them directly and invited them to participate.

The focus groups, triads, and some interviews were conducted at commercial focus group facilities located in the site visit cities. They were video taped. Some interviews were conducted in participants' homes or

offices. They were audio taped. We obtained informed consent from all participants prior to data collection using an instrument approved by the Institutional Review Board at RTI International. All subjects were paid incentives to participate, with dialysis patients and family members each receiving \$70.

We used semi-structured protocols as a basis for data collection in the focus groups, triads, and interviews. All were designed to last 2 hours, although some interviews ran longer. The protocols were prepared in consultation with Medicare staff, and were designed to cover the range of key topics and issues necessary to evaluate the Dialysis Facility Compare website. The protocols included a series of questions grouped into domains reflecting our research questions. For example, the protocol for dialysis patients included domains for the patient's experience of dialysis care, methods and information sources used to assess their care and to choose treatment facilities, impressions of the value of the information on the Dialysis Facility Compare website, and ways in which the website could be improved to provide more value to them. We showed participants the Dialysis Facility Compare website live on the Internet, and led them through it to gain their reactions and recommendations for improvement.

From April through July 2003 we also conducted telephone interviews with representatives of dialysis chains, managed care organizations, renal disease management organizations, and national dialysis stakeholder organizations. They were conducted using similar informed consent procedures and semi-structured protocols, but were designed to be 30 minutes in length. They were audio taped.

Overall, we conducted 19 focus groups, 13 triads, and 56 individual interviews that included 270 participants. [Table 1](#) presents the numbers of participants by type.

The 98 dialysis patients and family members included 75 patients and 23 family members. The 98 dialysis professionals and technicians included 9 nephrologists, 22 nurses, 29 social workers, 25 dieticians, 9 technicians, and 4 renal administrators. The 42 pre-dialysis patients and family members included 25 patients and 17 family members.

We analyzed each focus group and triad by coding and grouping participants' responses using a structured debriefing form. It contained a series of analytic categories developed from our research questions covering the care and information needs of patients and family members, participants' reactions to different sections of the website, and their recommendations for the ways it could be improved. We then combined and summarized the analyses for each analytic category across focus groups and triads.

Due to the larger numbers of interviews, we analyzed most of them using NVivo qualitative analysis software. Each participant's responses were recorded as text passages and then coded in the software using analytic categories similar to those used in the focus group and triad debriefer. This enabled us to identify each response associated with a given topic, even if it had been made in response to a different question. The text passages were then grouped by the software by code across the different interviews and combined. We integrated those results with the results from the focus groups and triads for analysis.

Our findings were first summarized in a series of themes identified within respondent groups. Themes that cut across the different respondent groups were also identified. Those related to integration of care are discussed in this paper.

## Results

We found that the Dialysis Facility Compare website has the potential to improve integration of care in several ways. This is important since dialysis patients face multiple challenges in maintaining their health, integrating ambulatory care, hospital care, and rehabilitation treatment, and managing the transitions of their disease over time. Specifically, the Dialysis Facility Compare website may promote integration through:

- Expanding the roles of patients as members of the multi-disciplinary team of caregivers treating their chronic kidney disease;
- Better integrating the informal care provided by family members in the home and community with the formal treatment provided by health professionals at medical facilities; and

- Improving coordination between care provided in the pre-dialysis and dialysis phases of chronic kidney disease.

Each of these findings is discussed below.

### Expanding patients' roles

We found that dialysis patients and family members have a strong interest in the continuing development of the Dialysis Facility Compare website, in its potential to aid them in better understanding and managing the care they receive, and in its potential to aid them in being more knowledgeable consumers of dialysis services and more effective collaborators with their clinical providers. They felt that they had been dependent on professional caregivers too long for information about dialysis and kidney disease. They welcomed the opportunity for direct access to data and information about dialysis quality of care, about dialysis treatment, and about their disease. As one patient put it, "This is the most information that I've seen in [over 10] years on dialysis." Patients appreciated the empowerment provided by the website for its own sake. They also saw benefits in terms of improved ability to work more collaboratively with their doctors and other caregivers, and to become more actively involved in managing their own care. Those expanded roles may enable patients to contribute to improving integration of care across providers and over time.

The Dialysis Facility Compare website currently provides some patient information resources through links to on-line publications and to related websites. However, patients and family members indicated they would like a range of additional educational materials to be available through the website. As one patient said, "You need to learn a lot of things. I still have so much to learn about dialysis." Professionals also supported this idea, often viewing this website as potentially valuable to them for patient education since their available time with patients is often limited. A selection of some topics frequently requested by patient and family member respondents include the following:

- More detailed descriptions of the different modalities and methods used in dialysis treatment.
- The patient's experience of treatment. For example, "What is it like to be on peritoneal dialysis?"
- The underlying causes of kidney disease, its anatomy and physiology, and its long-term implications.
- Dialysis-related self-care priorities (e.g. nutrition, vascular access) and potential health problems that may develop if they are neglected.
- A range of information on the option for kidney transplantation.

- The meaning of the laboratory test results patients receive.
- The implications of patient non-adherence to dialysis treatment. For example, “What happens if patients skip dialysis treatments or sign off early?”
- The rights and responsibilities of dialysis patients.

Expanding patients’ knowledge in these areas may benefit integration of care. For example, improved knowledge of self care priorities will help patients work more closely with their providers to prevent complications and promote earlier detection and treatment when they do occur.

We found that several patient sub-groups felt their needs were less well met by the existing Dialysis Facility Compare website. They suggested that the website focused too much on issues related to adult hemodialysis patients, the largest patient group. They indicated that this repeated a pattern they had previously and repeatedly observed in their dialysis facilities. As a result, it was something of a “sore point.” These sub-groups included the following:

- Dialysis family members;
- Peritoneal dialysis patients;
- Pre-dialysis patients;
- Parents of pediatric dialysis patients; and
- Spanish-speaking dialysis patients.

They expressed strong needs for additional website resources targeted to their particular concerns. They were seeking ways to expand their roles and viewed the website as a potential resource for that effort. These groups can play key roles in promoting integration of care if they are provided the knowledge and resources needed to fulfil those roles. For example, dialysis family members and parents of pediatric patients can aid in coordinating care when patients are feeling sick and being treated by multiple providers. Spanish speaking dialysis patients may face linguistic and cultural barriers to obtaining needed care, potentially hampering integration of care in multiple ways. Expanding their knowledge and self-management skills could help to mitigate those barriers.

## **Better integrating informal care and formal medical care**

Dialysis patients and their families must cope, on a daily basis, with multiple problems that affect every aspect of the patient’s life, including eating, drinking, sleeping, daily scheduling, physical activity, and family life. As noted, many suffer from serious comorbidities as well. Families and friends who support a chronically ill dialysis patient are faced with many challenges, including family and household issues, care and com-

fort of the patient, financial issues, meal planning, scheduling and transportation, and emotional factors. We found family members especially interested in ways to expand their roles to better support patients. They were seeking information to enable them to better serve as home-based caregivers and information intermediaries on issues important for patients’ health and well-being.

The severity of kidney failure means that enhancing family support roles is especially important for this disease. We found family members often viewed their roles as helping to assure that patients receive high quality care, or at least avoiding low quality care. They were seeking better information on quality standards for dialysis care, some of which are provided by the website.

Better integrating families and home-based care may have particular benefits by improving adherence to treatment. Non-adherence to dialysis treatments by patients is a common problem faced by dialysis professionals. It includes skipping dialysis treatments and signing off dialysis treatments early, before the prescribed time on the dialysis machine is completed [26]. It affects both morbidity and mortality of patients by preventing them from receiving adequate dialysis. This issue has been recognized as important for patients’ health by both the United States National Kidney Foundation and Medicare. Data on dialysis adequacy are included in the Dialysis Facility Compare website as one of the quality measures that can be used to evaluate the performance of dialysis facilities.

Two of the key methods used to address adherence are patient education and involvement and education for the patient’s family [29]. The Dialysis Facility Compare website can be used to support both those efforts. We found that family members wanted expanded access to information about the disease and its treatment methods, with the importance of adherence to regular dialysis treatments a key issue. The burden of attending hemodialysis treatments three times per week may weigh on patients, especially those suffering from common comorbidities such as diabetes and cardiovascular disease. Fatigue and depression are also common among dialysis patients and can affect adherence.

Family members highlighted this issue in our study, noting their multiple roles as informal caregivers, providers of social and emotional support, and transportation sources, all of which may be important for determining whether patients attend prescribed dialysis sessions and complete those they do attend. Adherence is also an important issue for care provided

directly in the home, including taking prescription medications at the appropriate intervals and dosages. Studies indicate that at least half of all patients fail to receive the full benefits of their medications due to inadequate adherence [30]. For dialysis patients that figure is likely worse due to the many different medications most of them take.

In our study, family members were vocal about their needs for more information to inform them about kidney disease and to provide ideas for ways they could enhance their roles to best help the patients, including better monitoring and coordinating the care provided by physicians and dialysis facility staff. They were less satisfied with the current Dialysis Facility Compare website than the patients. At the same time, we found that family members reported having Internet access more frequently than patients. Thus, their potential roles as information intermediaries for patients highlight the need to provide them with website resources they find beneficial and will use on a consistent basis.

### **Improving coordination between the pre-dialysis and dialysis phases of the disease**

We found that pre-dialysis patients typically have very little knowledge of kidney disease or dialysis. This was not unexpected, since patients are often asymptomatic in the pre-dialysis phase of the disease, and may not realize the need for early treatment. They may also be in psychological denial and avoid thinking or talking about their disease. However, this can be especially serious given the recent evidence that a range of early interventions can improve outcomes by slowing progression to kidney failure, reducing complications and comorbidities, and providing for a smoother transition to dialysis.

As we reviewed the Dialysis Facility Compare website with pre-dialysis patients, they often commented that they were learning about new types of information that they had not known to exist. As one patient described the website, "It enlightens me." This was striking, since we recruited these respondents through pre-dialysis educators, who referred patients who had completed their education programs. We expected these patients would be more knowledgeable due to the education they had received. Dialysis professionals also consistently reported that patients have little understanding of kidney disease or its treatment when they begin dialysis.

Family members of pre-dialysis patients were especially concerned about their lack of knowledge about

the disease and its treatment. We found them to need basic education on the clinical and self-care priorities for their relatives with the disease. Dialysis family members stressed the importance of learning about the disease early, in the pre-dialysis phase, since the first 6 months of kidney failure are often the hardest time for the patient and when they need the most support from their family members in dealing with the disease, with the transition to dialysis treatment, and with the multiple providers treating them. In addition, patients have fewer professionals working with them in the pre-dialysis phase, and thus may need to rely more on family members for information, support, and coordination of care.

We found that most pre-dialysis educational programs are still in the early stages of development. In our interviews, most pre-dialysis professionals reported providing a 2-hour class to participants on a group or one-on-one basis. A single 2-hour class is very short given the many issues that should be covered regarding care needed during this stage of the disease, methods for patient self-management, modality choice, placement of vascular access, the transplant option, the transition to dialysis, and others.

The pre-dialysis professionals were aware of the limitations of their programs, and indicated that funding was an issue that often limited the scope of their classes. This may indicate a need for alternate educational vehicles that patients or family members can access on their own, such as the Dialysis Facility Compare website. It also points to the potential role the website could play as a low-cost resource for pre-dialysis educators, both for in-class use and to show patients where they can obtain additional information.

### **Discussion**

The benefits of increased knowledge and active involvement of patients and families are sometimes included in discussions of integrated care, but usually the main focus is on supply-side factors affecting delivery systems and providers. Common supply-side interventions to promote integrated care include modifying organizational structures, expanding the scope of health care services provided, developing more comprehensive information systems, expanding staff roles, and developing multidisciplinary teams [31]. These efforts have had a number of positive effects. With the advent of managed care organizations and integrated health care systems, more is now known about how to provide the best care across specific settings and over time for people with chronic diseases. A major criticism of the United States health care system of the recent past was that care in each



specific setting was compartmentalized—each episode of care was treated as a discrete phenomenon instead of as a part of the larger endeavour, the ongoing provision of health care to the patient. Fragmentation of care remains a problem in the United States, but some progress has been made. The renewed emphasis on primary care has also begun to change the process of care; patients are now more often monitored by health care practitioners who appreciate the continuum of events that contribute to their patients' health status and functional capabilities.

Despite these improvements on the supply-side, the potential for patient and family interventions to improve integration of care needs to be more strongly emphasized. Pilon provided examples of how activating patients through patient and family education can aid in promoting integration of care [24]. She described several clinical applications relevant for kidney disease and its associated comorbidities: in-home glucose monitoring by diabetics; in-home blood pressure monitoring; and family-managed peritoneal dialysis at home.

The last example is noteworthy. Peritoneal dialysis requires the patient to engage in active self-treatment. It also enables the patient to be less dependent on dialysis facilities, providing increased mobility. As a result, many dialysis patients who continue to work choose peritoneal dialysis. However, one of the key issues in peritoneal dialysis is prevention and early detection and treatment of peritonitis, a potentially severe infection that often requires hospitalization. For that complication, patients and family members can play an important role by carefully integrating their efforts with physicians and other health professionals. The more vigilant patients are about sterile procedures and testing for early signs of peritonitis, the fewer infections they will have.

Efforts at improving patient-physician communication and enhancing the patient's sense of control through participation in treatment decisions have been shown in several studies to improve adherence to medications and other treatments, improve outcomes, and improve patient satisfaction [32]. Two of the key elements of those programs have been effective communications with patients and enhancing family involvement to complement efforts directed at patients.

We discuss below the implications of our three main findings related to patient activation and integrated care. They included recommendations for improvement of the Dialysis Facility Compare website to better promote patient activation. The recommendations were developed from respondents' recommendations, our assessment of those recommendations, our own

analysis of the strengths and weaknesses of the website, and our experience with other website development and evaluation projects.

## **Expanding patients' roles**

We recommended that the Dialysis Facility Compare website provide increased patient access to information primarily through expanding the number and range of its hyperlinks to other websites, rather than placing information on this website that may also be available elsewhere. That approach could also further the underlying goal of the Dialysis Facility Compare website to promote patient self-management through the process of seeking out knowledge on other websites. We also recommended that special hyperlinks be set up within Dialysis Facility Compare for the subgroups we found to be less satisfied with the website, so that they could see explicitly that their particular information needs were being addressed. For example, we recommended that a Spanish-language version of the Dialysis Facility Compare website be developed; this was frequently suggested by respondents in our study.

Some examples of useful websites for pre-dialysis and dialysis patients include [www.kidney.org](http://www.kidney.org), sponsored by the National Kidney Foundation, and [www.aakp.org](http://www.aakp.org), sponsored by the American Association of Kidney Patients. Both offer a range of information and resources for hemodialysis, peritoneal dialysis, and pre-dialysis patients. Patient education resources developed by the Life Options Rehabilitation Program are available at [www.kidneyschool.org](http://www.kidneyschool.org). That website features a series of 16 personalized, interactive modules focused on helping patients learn skills for self-management of their disease. All of these websites also contain links to many other websites that can help promote patient and family self-management for people with chronic kidney disease. They illustrate how the hyperlink capabilities of the Internet can provide a unique resource for activating patients and promoting integration of care.

We also recommended that lists of questions and checklists be added to the Dialysis Facility Compare website, so that patients and family members could have guidance on questions to ask when they visit dialysis facilities or discuss kidney disease with their doctors or other providers. This could 'coach' patients on ways they can become more involved in their care and better able to integrate care across providers and over time. Patients indicated they would like to engage their providers more actively, but were unsure of what questions to ask.

## **Better integrating informal care and formal medical care**

The long-term nature of chronic illnesses, and the emotional toll they take on family relationships, often mean that spouses and other family caregivers are at risk for fatigue, depression, or 'burn out,' situations that can result in a breakdown of key support systems for patients [33]. In addition, the trend in the United States toward reducing hospital lengths of stay means that patients are discharged home typically sicker than they used to be, further adding to the burden of family caregivers. As a result, family members have personal incentives to mitigate their burdens by bolstering their own knowledge of kidney disease and promoting integration of care, in addition to their goal of improving care for their relatives.

We recommended two ways that the website could be modified to better respond to the needs of family members. First, development of a special web page that provides information explicitly for family members. That would identify the website as a resource also for family members, and not just one that provides information for patients and dialysis professionals. It would acknowledge the unique roles of family members, and the unique information needs that often accompany those roles. It would contain model questions that family members could ask physicians and dialysis facility staff to help them better understand the ways they can help patients, and to promote more effective collaboration with those professionals.

Second, a series of external website links would provide additional educational resources for family members. These could draw on lessons and examples from other chronic diseases as well as from kidney disease. Family members can find useful information at [www.caregiver.org](http://www.caregiver.org), sponsored by the Family Caregiver Alliance, which offers fact sheets, newsletters, and access to support groups. Parents of pediatric patients can access the NephKids website at [cnserv0.nkf.med.ualberta.ca/NEPHKIDS](http://cnserv0.nkf.med.ualberta.ca/NEPHKIDS). It includes information, links, and an on-line support group moderated by pediatric nephrologists. Family members can benefit from these websites by understanding the ways in which their issues and challenges are shared by many others, and learn useful techniques for managing patient care issues at home.

## **Improving coordination between the pre-dialysis and dialysis phases of the disease**

The goals of increasing patient self-management and involvement in treatment decision making may be best

achieved by starting early in the disease process, in the pre-dialysis stage. In that way patients' expectations and habits of active involvement in their care could start early and be more easily sustained after the transition to dialysis. As a result, improvements in integrated care may be promoted more strongly by expanding the knowledge and activation of pre-dialysis patients.

We recommended two approaches for revising the Dialysis Facility Compare website to expand its outreach to pre-dialysis patients. First, development of a special web page that provides information explicitly for pre-dialysis patients and their family members. As with dialysis family members, this would identify the website as a resource also intended for pre-dialysis patients, and not just one for patients who have already progressed to the need for dialysis. It could contain model questions that pre-dialysis patients could ask physicians and dialysis facility staff to help them to better understand the disease and better ensure active collaboration with doctors and other professionals. It could also contain a series of external website links to provide additional educational resources for those patients and their family members.

Second, we recommended development of Dialysis Facility Compare-based modules or scenarios for pre-dialysis educators to use in their classes. These modules might include practice in accessing links to patient educational resources or exercises for investigating dialysis facilities in a new city to which patients might be moving or travelling. A more modest approach might be to provide educators with examples for demonstrating some of the capabilities and links provided by the Dialysis Facility Compare website. Instead of simply including the website in a longer list of additional patient resources, these examples could get patients involved in "hands-on" exploration of the website during or after pre-dialysis classes. In that way, patients would be more likely to retain the information and return to the website, since they would be familiar with its potential benefits.

## **Future issues**

In the future, Internet applications for patient communications may increasingly adopt strategies based on constructs from behavioral theory. Social cognitive theory, for example, identifies a significant role for social modelling, or learning by observing the behavior of others [3]. Web users might access visual presentations of relevant "models" of their own age, race, or gender performing important health-related behaviors. Multiple models or scenarios could be stored on

websites and selected for presentation based on patient responses or requests.

Future website applications may also explore the benefits of different aspects of the Internet's unique features, such as interactivity. For example, one definition of interactivity includes six dimensions [4]:

- Complexity of choice—The range of content options from which users can choose to satisfy their preferences and information needs. The more content, the better the ability to develop a message that is narrowly tailored to the individual.
- Effort exerted by users—The process of selecting and navigating through content. The more users can be persuaded to play an active role in selecting and processing content, the greater the likelihood that the message will be effective.
- Responsiveness—The precision of feedback in message-tailoring efforts. Websites that are more responsive to users' needs are more likely to be effective.
- Monitoring of information use—The ability to continuously evaluate utilization of website features and services, and adapt quickly to changing preferences of users.
- Ease of adding information—The extent to which the website allows users to modify content.
- Facilitating interpersonal communication—The ease with which users are able to communicate with each other.

Most websites will probably only pursue a subset of these six aspects of interactivity, but the list does illustrate the range of options available with Internet technology. Others are possible as well.

Along with possible new applications, potential problem areas with Internet-based efforts to expand patient involvement and integration of care also need to be addressed. For example, physicians may resist efforts to expand the roles of patients and their family members as partners in treatment and care [34]. This may result from practical concerns regarding the time required or availability of appropriate information for patients. It may also result from physicians' concerns about their own ability to communicate effectively with patients, the potential for patient preferences to conflict with their own, or a desire to maintain the traditional imbalance of power between themselves and their patients [34]. Physicians may also simply be pessimistic about patients' ability to make the behavior changes necessary to become more active in self-management of their diseases [32]. Training of physicians in methods for working with empowered, self-managing patients is needed to complement patient and family education regarding those roles.

Concerns are sometimes raised about the availability of Internet access for chronically ill populations, who may also have low incomes and face other barriers. However, in our study we found Internet access to be less of a problem for dialysis patients than we expected. Family, friends, and local libraries were often cited as sources of Internet access for patients who did not own computers. It may be that Internet access in itself will not be the major barrier to use of websites such as Dialysis Facility Compare, as some have suggested, but rather the key will be to ensure that patients believe that they can gain tangible benefits from using the websites. That would then motivate them to more actively seek Internet access through public facilities or their social networks.

Our study had several limitations. First, the subjects were all residents of the United States. Websites developed in other countries may have more or less potential to influence patient activation and integration of care. They may also face different needs and preferences from patients and family members, and may need to be implemented in different ways. Second, our subjects were volunteers who may have been more comfortable with Internet technology than other chronic kidney disease patients and family members. Nonetheless, we expect that familiarity and use of the Internet will expand in all populations in years to come. Third, our study was conducted on an early version of the Dialysis Facility Compare website. As the website is revised and enhanced, further research will be needed to assess its impact and potential.

In sum, the dialysis patients in our study were interested in activating their roles and saw the Internet as a useful tool toward that end. We found a keen interest in the continuing development of the Dialysis Facility Compare website across all types of respondents in our study, including patients, family members, and professionals. Many suggested that the website needed revision and improvement in a number of areas, but they still saw it as having great potential to expand patient knowledge and involvement. We believe that those types of expanded roles for patients and family members have the potential to promote integration of care in multiple ways.

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