Encyclopedia of E-Health and Telemedicine

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Distance Education in Telemedicine and M-Health Initiatives in Therapeutic Patient Education

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INTRODUCTION

Patient education is a critical component of 21st century health care. On a policy level, initiatives such as the United States government's Healthy People 2000, 2010 and 2020 programs encourage all citizens to participate in health promotion and disease prevention, regardless of whether they are health care professionals, patients being treated for a condition or disease, or individuals who consider themselves in perfect health (U.S. Department of Health and Human Services, 2013). Practically, patients' participation in health care assessments has been associated with improved outcomes. Involvement in treatment decisions increases patient motivation, adherence and satisfaction (Dreeben, 2009). Individuals' ability to contribute to the conversation about their treatment is increased by their own knowledge of and comfort with discussing their condition or just the state of their health.

The increased role that the internet plays in our lives, and the prevalence of mobile technology in society, has increased the viability of distance education in general, and the health care industry is seeking to apply distance learning methodology and technology to the challenge of providing improved patient education. There has long been a recognition that patient care extended beyond the hospital or doctor's office, and while the health care industry is notoriously slow in adopting and integrating information technologies (due to a variety of factors, but most understandably concerns about the privacy and security of patient data), efforts to include computing and communication advancements into the field date back decades (White, Krousel-Wood & Mather, 2001). The Institute of Medicine, for instance, introduced the term "telemedicine" in 1996, defining it as the "use of electronic information and communication technologies to provide and support health care when distance separates the participants" (White et al., 2001, p. 22). In tandem with an integration of communication technology to the field, health care should also be utilizing the knowledge and experience of education and instructional design professionals to their efforts at patient education. This paper will analyze where past programs have achieved their goals or struggled as evidence that the best practices of distance education being employed in other industries are also key to success in health and medicine. It will also provide three recent examples of telemedicine and mHealth applications that are applying the lessons learned from previous efforts and examine their prospects for success based on current research in educational design.

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A Brief History of Distance Education, Technology, and Health Care

Initial telemedicine efforts focused on professional education for providers and increasing accessibility of health information for the public. Using the internet to make vast amounts of information available to anyone with a networked device greatly increased the number of people with access to medical literature, but not all websites have policies in place to ensure the credibility and validity of information the way that government, academic and other institutions with accountability do (Codyre, 2014). In fact, considerable cost and effort has been required to counter anecdotal concerns of private citizens, such as the movement to discourage parents from vaccinating their children because of beliefs that the vaccines increase the risk of autism (Bruni, 2014). While increasing the amount of information that the public has access to is beneficial, there are challenges and the industry has learned that a website does not equal education. Health care is information intensive, not just for education flowing from providers to patients, but for data from individuals to doctors and nurses on how they are feeling, how treatments and medicines are affecting them and their concerns about their conditions and suggested courses of action. This is another reason why the initial wave of websites full of articles, however informative, was not a successful application of distance learning for health care. A meaningful patient education program requires a component whereby the user can provide feedback to their treatment professionals.

Much subsequent development in telemedicine focused on monitoring patients' conditions, gathering diagnostic information and ensuring compliance with treatment guidelines. While initially beneficial to researchers and those directing treatment, these applications provided little incentive for continued patient participation and demonstrated diminishing returns the longer the program continued (Seto et al., 2012).

Despite the lack of initial success in implementing technology to create patient distance education programs, the need for and benefit of patient education continues to be driven by a number of factors, and results in continued and varied attempts to create distance education applications for patients. Early education efforts on chronic conditions such as diabetes and asthma have been shown to improve morbidity and mortality rates, reduce patient anxiety and decrease cost of treatment (Golper, 2001). Cost and increased demand is also a driver of rapid discharge from health care facilities, which results in more patients being responsible for managing their own health earlier in the recovery process (Dreeben, 2009). This also reduces the time where patients would interact face-to-face with the providers who would have in the past been educating them on their condition and treatment, necessitating effective means of facilitating that learning at a distance.

Lessons Learned from Previous Telemedicine and M-Health Applications

This increased need combined with the rise in the availability of communication technology has led to a number of applications and programs designed to provide patient education at a distance. In the rush to provide services to patients, providers and organizations, the health care industry would benefit from increased input from the field of education and instructional design in determining how to maximize the effectiveness of their distance learning programs. An analysis of where distance applications of patient education have succeeded or experienced challenges is useful in tailoring that input. The health care and education fields have learned many of the same lessons simultaneously with regards to what works and what doesn't.

CONDITIONS CONTRIBUTING TO SUCCESSFUL OUTCOMES

Internet-based programs demonstrate greater effectiveness than control groups consisting of patients who only interact with providers during office visits when geographic distance limits their access to those interactions (Griffiths & Christensen, 2007). What's hopeful is that this benefit is significant regardless of other design best practices being in place, meaning that patients in rural, developing or other remote areas should see exponential improvement from being offered a distance learning program that integrates other proven features.

Patients dealing with conditions that bring with them a social stigma, such as mental health or additions, show significant successful outcomes when presented with distance education options (Harrison et al, 2011). The interpersonal anonymity of dealing with professionals and fellow patients via the internet or a smartphone application removes one barrier for individuals who might be hesitant to otherwise identify as sufferers or engage in treatment.

Behaviors or lifestyle changes that a patient is already motivated to participate in can be encouraged and supported successfully with distance learning. This is especially helpful in addressing secondary factors that contribute to a wide range of health issues, such as eliminating the use of tobacco products. Programs focused on heart disease and diabetes have shown improvements in weight loss and smoking cessation; changes that can lessen the impact of the condition that is the primary focus of the education effort, but also benefit the person's overall health outlook (Vodopivec-Jamsek, de Jongh, Gurol-Urganci, Atun & Car, 2012).

The more immediately the benefits of participation in a program will be felt, the more likely patients are to engage in the process. For conditions where success means maintaining a given level of treatment, such as insulin therapy for diabetes or a continued course of drugs for HIV/AIDS, taking part in education about the disease or condition can feel like an added responsibility without any benefit. With something like asthma or depression where education can provide tools that impact the frequency or severity of acute episodes, patients are more likely to participate in an ongoing education program (de Jongh, Gurol-Urganci, Vodopivec-Jamesek, Car & Atun, 2012).

Barriers to Successful Outcomes

Some of the challenges of a distance or technology-aided patient education program have already been discussed, such as ensuring quality of information. This takes on an added dimension given the necessity of creating learning events that break through the noise of other websites or mobile applications competing for a user's attention, and when developers attempt to integrate a social component to a program – which we will see can greatly increase its effectiveness, but also increase the potential for incorrect information or bad data.

While many patients grew up with the internet and younger people are increasingly relying on mobile and smart phones as their primary means of communication, many who might benefit the most from a patient education program are older, or from a demographic that is limited in access to or familiarity and comfort with information technology (Kamel Boulos, Wheeler, Tavares & Jones, 2011). This can place an additional burden on providers and institutions to provide preliminary education, support and motivation or even devices themselves to patients who might benefit from an educational application.

A major challenge of any ongoing education effort is learner retention, and patient education is no different. As people begin to feel healthier and as time passes from an inciting acute incident, patients will be less motivated to engage with an ongoing education program. They may learn some tools that

change behaviors, leading to better outcomes, during the time that they are participating, but even if that is the case, failing to retain learners limits the amount of data that providers can collect from patients. It can also mean that patients may not be available to receive modified instructions or information about new developments regarding their condition.

Keys to a Telemedicine or M-Health Design that Will Succeed

Can those challenges be overcome, and success achieved with patients who don't have issues or conditions that mirror those of previous cases where results were seen? Common best practices for distance education in any field should be met in order for a telemedicine or mHealth application to achieve results.

The application needs to feel tailored to the user. It should present as a unique way for a patient to learn how to better manage their condition or adhere to treatment in order to improve their quality of life. Programs where the focus is solely or largely on monitoring adherence to a regimen or collecting data will be seen as an added responsibility or burden for the user. Even without those components, an information heavy application may leave patients feeling as if they are being pushed to a website or app to limit their time with a doctor or health practitioner. Any effort where the learner believes they're being placated or given a cheaper alternative to the type of interaction they prefer will face an uphill battle to succeed.

Information provided should feel tailored to the individual user, or customizable for their experience. Ideally, this would be accomplished by providing real life interaction, either with medical professionals or others dealing with the same condition. A blended learning environment with video information sessions is one approach; better still are programs that integrate video or internet conferencing components where users can interact with experts one-on-one or in groups to ask questions or share their experiences (Välimäki et al, 2012). Incorporating an element such as this into the design also serves to provide caregivers with another means of collecting data that can be useful in research, future development of the therapeutic distance education program or the treatment of other patients.

Perhaps most importantly, the application must motivate the user beyond just learning about a disease or condition. The goal of therapeutic patient education is of course to educate, but the information has to drive the patient to action in order for recovery to occur or for quality of life to improve. A Type II diabetic will not reverse the course of their disease, nor will an addict abstain from drugs and alcohol, by increasing their knowledge without changing their behaviors. Providing a means for health care professionals and fellow sufferers to interact with a user is probably the most effective means of encouraging new behaviors, but there are other means such as gamification and other rewards systems that can facilitate learning into action (Martin, Williams, Haskard & DiMatteo, 2005).

MODELS FOR THE FUTURE

Three recent patient education and therapeutic support efforts have taken different approaches to the challenge of supporting patients beyond the physical walls of a doctor's office or hospital. Aimed at different audiences dealing with different diseases, they combine the education element with interaction, an incentive system, or both to go beyond being a one-way delivery system for information and to engage users in a way that they would not otherwise be engaged without having a face-to-face interaction.

Chrobev, Sotirovska and Mihajlov have developed a virtual community for diabetes care that encompasses many of the best practices advocated for in this paper (2011). Their system, Diabetes Mobile Virtual Platform (DMVP) is based upon Microsoft network protocols, in order to both allow for their system to be accessed from a wide variety of computing and mobile devices, but also to ensure secure data transmission of data from patient to network in order to provide a customized experience for the user. People with diabetes or their caregivers can register through a secure maintenance service. Users are authenticated but can interact with a self-chosen username once private information is entered. Medical specialists are registered via an identical but separate maintenance service, and interact with the community in general and with specifically assigned patients.

The system those two services connect then provides education and support to patient members in three ways. First, guidance and advice is customized based on user input. A person with diabetes or their family members can read and receive standard information similar to what may be presented on a one-way website, but they also have the opportunity to enter personal information or health parameters (such as blood sugar concentration) in order to receive assistance specifically tailored to them. This also provides an incentive for users to supply data that medical professionals can use in their work. DMVP also has a social collaboration piece, which provides a forum within which users can exchange experiences and advice among themselves. This can be a critical piece for motivation, especially if the user resides in an area without face-to-face support groups. Users can add others to their networks and designate a "level of trust" based on familiarity and quality of advice or support. Professional health care supports are also placed into groups as either personal physicians or temporary advice givers. Lastly, the system ties into the patient's traditional care network, and provides notification of appointments, prescription refill reminders and referrals to support services. Though the initial rollout of the system was small, 94.3% of users surveyed described the usefulness and data content of the service as "Very Good" or "Excellent". Users expect continuous system improvements, and those will be necessary to keep users engaged in order to motivate them to remain in the network, but DMVP presents a good start at a comprehensive therapeutic solution which incorporates distance education best practices.

A Canadian team has developed an iPhone application designed to improve pain management for children with cancer (Stinson et al, 2013). The primary challenge identified by the team was that patients often "hoard" assessment data and report in bulk, often with inaccurate recollections of their situation – in this case, the amount of pain they were experiencing as a result of cancer and cancer treatments.

Their solution was Pain Squad, a game-based application designed for the iPhone which provides a narrative framework for the traditional pain diaries that treatment teams use to manage and track those responses. The system, designed with Apple iOS code on the user end with a Microsoft SQL database on the back-end to securely catalog user data and responses, tells the story of a police team whose mission is to "hunt down pain and put it behind bars". Adolescent patients are prompted twice a day to complete a questionnaire via a touchscreen interface. Filling out three consecutive reports results in a promotion within the squad, and an educational/motivational video message from stars of Canadian-filmed television shows featuring police characters.

In addition to the rewards-based aspect for encouraging participation, patients are contacted by a member of their treatment team if they report severe pain on two consecutive assessments, so users and their families see a practical benefit to use of the application. Similarly, pain management strategies that are presented as feedback (with promotions or with daily report reminders) are tailored based on previous reports so that each user receives information specific to their reported condition.

Compliance and satisfaction data in short-term testing was positive. The mean completion rate for the twice daily assessments was 81%, and 86% of users reported that they "very much liked it" or "liked I okay". While a game-based system without rules or objectives may be limited in its long-term appeal to adolescents or other users, the idea behind Pain Squad shows promise as part of a more comprehensive mHealth education effort.

These approaches are melded in A-CHESS, or the Addiction-Comprehensive Health Enhancement Support System (Gustafson et al, 2014). Developed at the University of Wisconsin-Madison, the smartphone application has been provided to recovering alcohol abusers who are leaving rehabilitation centers and navigating life in their first year of recovery. The version tested includes guided relaxation education, games to occupy users when cravings strike and a "panic" button which connects patients with support staff and other users if they feel particularly at risk of relapse. Compared to a control group that received standard post-rehabilitation support without the smartphone app, A-CHESS users experienced less occurrences of "risky drinking" (where users had more than three or four drinks in a two hour period). More encouragingly, 52% of the test group remained alcohol-free after twelve months, as opposed to 40% of the non-app group.

In addition to the success of A-CHESS, it also provides a model for long-term cost savings. It is estimated that use of the app during the 12 months of the study cost $597 per user (Seaman, 2014). Those costs are likely to go down as smartphones and data plans become more affordable. Face-to-face rehabilitation support can cost thousands of dollars per client and makes up a significant portion of the estimated $184.6 billion dollars spent on alcohol abuse and dependence in the United States each year (Seaman, 2014).

CONCLUSION/RECOMMENDATIONS

With a worldwide focus on offering better quality of medical care to more people while reducing costs, all options that can accomplish that will receive some attention. One-on-one interaction with doctors, nurses and other medical professionals is an obvious cost-center, but the challenge for programs and initiatives that limit that interaction is to maintain care levels as clients become more responsible for their own treatment.

Telemedicine and mHealth initiatives are a viable option for educating and assisting patients in maintaining their own well-being. Regardless of the technology used, therapeutic patient education must incorporate research and best practices from the field of education – specifically distance education, eLearning and mLearning. In examining what other applications of distance learning can show the health care industry about engaging users and transforming information into action, developers in the field of health and medicine must also investigate the specifics of each culture and condition for which they are creating a solution. Attempting to invent one size fits all solutions or present an information dump as a well-rounded program will fail to meet the objectives of patients, medical professionals and the organizations for whom they work.

Close attention to quality and control of information, patient motivation and immediate user benefits and a created a tailored, interactive experience for the patient can result in applications that assist in keeping patients engaged so that they can better manager their care and provide more timely and relevant data on their treatment and conditions. Both outcomes will result in lower cost for the system, thereby meeting everyone's goals.

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