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DEVELOPMENT OF *MY HEALTH COMPANION*® TO ENHANCE SELF-CARE MANAGEMENT OF CHRONIC HEALTH CONDITIONS IN RURAL DWELLERS

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Abstract

Appropriate self-management support is needed to help individuals and their families meet the challenges of living with chronic health conditions. Such support is characterized by productive interactions between informed, active individuals and their health care providers. The purposes of this paper are to describe the challenges to achieving self-management support and a tool, *My Health Companion*® (*MHC*), which was developed to meet that challenge. The *MHC* is a paper personal health record designed to help rural women with chronic health conditions to better manage and understand their health information. The selection of content for the *MHC* was based on the literature, input from health care experts, and chronically ill individuals, and its development incorporated principles of personal health records and clear communication. The *MHC* was anecdotally shown to be useful to rural women with chronic health conditions in preparing for and enhancing their visits with health care providers. As a source of information, the *MHC* had potential for: being beneficial to providers in recommending appropriate treatment; contributing to more informed health decision making by ill individuals; and serving as a vehicle for the establishment of more productive interactions that contributed to the achievement of true client-provider partnerships in health care.

Keywords

self-care management; health literacy; personal health record; chronic illness; client/provider relationships

Managing a chronic health condition is challenging, to say the least. A common set of challenges for individuals and their families includes dealing with symptoms, disability, complex medication regimes, obtaining appropriate medical care, and adjusting to the impact of all these impositions on their life style and emotional well-being (Wagner, Austin, Davis, Hindmarsh, Schaefer, & Bonomi, 2001). Dealing with these challenges in a rural environment with its limited resources becomes even more daunting.

In an effort to address the challenges of managing chronic illness, Wagner and colleagues developed the Chronic Care Model (CCM) to enhance productive interactions between an informed and activated individual and his or her health care providers in the comprehensive, ongoing management of the client's chronic illness(es) (Bodenheimer, Lorig, Holman, &

Grumbach, 2002). This model of providing quality care for chronic health conditions represents a comprehensive system approach that includes the essential elements of community, health system, self-management support, delivery system design, decision support, and clinical information systems. Optimal combinations of these elements enhance health literacy and foster productive interactions between informed individuals who take an active part in their care and properly prepared providers who offer resources and expertise. When informed individuals take an active role in managing their health and providers feel prepared and supported with time and resources, their interactions are likely to be much more productive. This kind of productive interaction leads to healthier consumers and more satisfied providers (Wagner et al., 2001).

Background

One of the key elements of the CCM is self-management support. Effective self-management means that individuals have a sense of responsibility for their own health and assume a central role in determining their care (Robert Wood Johnson Foundation, 2003). Productive interactions between client and health care provider require that the individual and her/his family have the knowledge, skills and confidence to manage his/her condition(s). It is important to re-emphasize that effective self-management is very different from telling individuals what to do; instead, they are assisted to assume responsibility for their health (Robert Wood Johnson Foundation). Success in this endeavor requires the support of health care providers, family members, and community.

In order for individuals to become informed so that they can take an active role in managing their health, they must be able to obtain, read, understand, and act on health related information; that is, to be health literate (Partnership for Clear Health Communication Steering Committee, 2003). Health literacy has been touted as the strongest predictor of an individual's health status, more so than age, income, employment status, education, or race/ethnicity (Seminole County Patient Safety Initiative, 2006). Likewise, low health literacy has been dubbed "a silent epidemic threatening the quality of health care" (Boodman, 2007). The degree of health literacy influences the ability of individuals to monitor their health, understand health care providers' recommendations, and productively engage with the health care system. A key component of overall health literacy is management of health information which can be enhanced with the use of a personal health record.

Personal health records (PHRs) can empower consumers to become more effective managers of their own health information and care. This record makes it possible for individuals to maintain their own complete, updated, and easily accessible health data on which to make health decisions and which can be shared with health care providers, family members, and other caregivers as they deem appropriate. Because the PHR is owned, controlled, and managed by the individual, it positions him/her at the center of the health care process and provides a more complete and balanced view of his/her health profile (Ball, Smith, & Bakalar, 2007). Among the benefits of PHRs listed by Endsley, Kibbe, Linars, & Clorafi (2006) were: empowerment of individuals (very useful in chronic disease management), improved individual-provider relationships; increased individual safety; improved quality of care; and more efficient delivery of care. There is no question that the idea of empowering individuals to manage their health care through the use of a personal health record has widespread support (AHIMA/AMIA, 2007).

Although electronic PHRs are being touted in the current techno-environment, there is much to be said for the low-tech, consumer-maintained paper-based record that includes lists of medications and allergies, illness patterns, and treatment plan, along with other vital information. With a paper record in hand, the individual can walk into any office with

confidence that it can be read and understood. This is not necessarily true for the electronic PHR on a disk, CD, or memory stick. Even those who use these formats admit to printing out copies of their electronic record to take to appointments. In spite of the initiative to create an interoperable Nationwide Health Information Network that is bringing the electronic PHR front and center (Tang, Ash, Bates, Overhage, & Sands, 2006), the paper record is still a viable alternative in the interim. It is of particular use in rural environments where long distances from health care centers and multiple referrals for care unavailable from local health care providers complicate health care system communication.

The purposes of this paper are to describe the challenges to achieving self-management support and a tool, *My Health Companion*® (*MHC*), which was developed in an effort to meet that challenge. The *MHC* provides a structure for tracking and maintaining health information and enhancing health literacy. Such a health information management tool can facilitate more informed decision making and foster productive interactions with the health care system, particularly in rural environments.

Challenges to Achieving Self-management Support

Unfortunately, many health care delivery systems have not effectively incorporated the CCM elements. Consequently, self-management support may be more the exception than the rule, especially in rural environments where there can be unique challenges to attaining health care access and quality. Problems of access to quality care include shortages of health personnel, transportation and distance barriers to care (Isaac & Reed, 2008), and less than optimal client-health care provider relationships (Weinert, Whitney, Hill, & Cudney, 2006).

These rural challenges were found to be very real to nearly 800 middle-aged women with chronic illnesses living in the rural west and who participated in the Women to Women (WTW) project, a computer-based support and education research program (Hill, Weinert, & Cudney, 2006; Weinert, Cudney, & Hill, 2008; Weinert, Cudney, & Winters, 2005). The overall goal of WTW was to enhance the women's adaptation to living with chronic health conditions. Participants were randomly assigned to either a computer intervention that provided health information and social support or a control group which received no intervention. Those who participated in the intervention completed informative research team-generated online health teaching units and exchanged messages of support and information in asynchronous online forums. Since the forums were for and by the women, with the research team primarily relegated to a monitoring role, they freely voiced their experiences, concerns, and frustrations related to living with chronic illness, including comments about their relationships with the health care system and their health care providers. The ongoing study was approved by the Montana State University Institutional Review Board for the Protection of Human Subjects.

Some participants in the WTW project described traveling many miles at great expense, discomfort of a long distance ride, compromised safety on snow covered roads, and inconvenience in needing to find coverage to care for farm animals in their absence in order to keep doctor's appointments. Often upon arrival they were allotted only a brief time (as short as 10 minutes) with the health care provider with no time or opportunity to have their concerns addressed or questions answered—the antithesis to productive interactions between clients and providers.

However, in the face of these barriers to productive client-provider interactions, some of the women were resilient and proactive in finding ways to handle these challenges. The following excerpt from a posted message demonstrated how one woman's dissatisfaction with her interactions with a non-responsive rural health care system led her to become more prepared and organized for her future encounters:

At first I was hurt but [the experience] encouraged me to use the Internet to prepare an organized medical profile.... My ever ready lists with questions put me in the driver's seat. I was organized and I like myself for it!

Further, the women expressed appreciation for those providers who included them in the process of managing illness, and decried those who failed to include them in treatment decisions. Providers who were knowledgeable and willing to provide education concerning the women's illnesses were particularly valued. Throughout their messages, the women expressed the desire to be listened to, receive clear explanations of their conditions and therapies, and be given the opportunity to take part in health care decision-making (Weinert et al., 2006). They were open to being informed, activated partners in their health care, and eager for the support required from health care providers, family, and community to attain this goal.

Development of *My Health Companion*®

As can be seen, the need for the development of *My Health Companion*® (*MHC*) arose from the expressed needs of women in the WTW program for more productive interactions with their health care providers and better control of their health and health care, as well as from the experiences of the research team's advanced practice nurses in providing quality care. The *MHC*, a portable health record, is a means of maintaining individuals' updated health information, increasing their health literacy, and contributing to a more active client/care provider partnership. The development tasks involved included: defining the content, establishing an appropriate reading level for the *MHC* and related materials, and planning participant orientation to the *MHC*.

Defining Content

The intent, in developing the *MHC*, was to include information that would paint a picture of the individual and the impact of her/his illness on life style, rather than follow a more structured health history model. Although much standard information was incorporated into the *MHC*, we went beyond the traditional approach to offer opportunities for recording the person's emotional status and spiritual and social resources.

The content of the *MHC* was refined based on the literature (AHIMA/AMIA, 2007; Federal Citizen Information Center, 2008; Lansky & Brennan, 2004; National Education Association, 2008), discussions with WTW team members, and results of piloting the *MHC* with selected chronically ill individuals. In addition, the team concurred it was important to incorporate five of 10 AMIA/AHIMA (2007) Principles of a PHR that were most pertinent to paper PHRs (see Table 1).

Establishing Readability Level of the *MHC* and Related Materials

Because the *MHC* was first used as an adjunct to the WTW computer outreach project, the participants were introduced to an explanation of its background, purpose, and use through one of the project's online health teaching units. To ensure that information in the *MHC* and the online health teaching unit would be understandable to the individual, the issue of health literacy was considered in the developmental process. That is, for maximum utilization of the *MHC*, it was necessary that the women could read and understand the health information associated with it (Partnership for Clear Health Communication Steering Committee, 2003).

The Gunning Fog Index (Gunning, 1969) was used to determine the readability of the *MCH* and its supporting health teaching unit—that is, to show how easy or difficult a text is to read. It uses the following formula: Reading level (Grade) = Average number of words in sentences + percentage of words of three or more syllables × 0.4. The resulting number is

the Gunning Fog Index, and provides the years of education a reader will need in order to understand the paragraph or text (Usingenglish.com, 2008). Materials written for people with a potential for lower health literacy should be aimed at the sixth-grade reading level (Partnership for Clear Health Communication Steering Committee, 2003). Thus, to ensure maximum utility of the *MHC* and unit, the sixth-grade reading level was selected as appropriate. In addition, the supporting health teaching unit was designed using Pfizer's "Five Principles for Clear Communication" (Partnership for Clear Health Communication Steering Committee, 2003). Utilization of these principles (see Table 2) can further enhance the women's health literacy.

Planning Participant Orientation to the *MHC*

In its development and early testing phase, the *MHC* was introduced to the participants through their completion of the *MHC* instructional online health teaching unit in the third week of the WTW intervention. This exercise prepared them to accurately record their health information in the *MHC*. The topics addressed in the *My Health Companion*® health teaching unit were: a) importance of claiming "ownership" of chronic illness, b) rationale for keeping a health record, c) ways to use the *MHC*, d) recognition that health ebbs and flows, so information changes, e) writing in the *MHC*, f) overview of each section in the *MHC*, g) claiming ownership revisited, h) discussion of ideas about the *MHC*, i) rewards for the week, and j) Web-site references. Hard-copy pages of the *MHC* were provided in a 1 ½ × 11 three-ring notebook binder with dividers for each section. The titles of the sections of the *MHC* are: a) Basic Information, b) Health History, c) Health Information, d) Medical Record and Preventive Care, e) Laboratory Tests, f) Support System, g) Questions for Health Care Provider, h) Insurance Information, and i) References and Additional Information. More detailed information on each section can be found on Table 3.

Utility of *My Health Companion*®

While the *MHC* is in the early stages of use and testing, promising feedback on its utility has been provided by some participants in WTW. One woman contacted us to say, "I just had to call and let you know how much I love *My Health Companion*®. Now I am really organized when I go to see the doctor." Another participant posted the following message in the forum:

Well, I got all my information all filled out in *My Health Companion*®...I had got my records from the clinic and got a list of all my meds that I have ever been on and wrote why I quit them and if I was allergic to them or not...It is pretty cool to look back on. In fact when I went to my new neurologist he was asking if I had ever tried a certain medication and I just looked it up so quickly...He was very impressed with the Women to Women program after I explained it to him...He said he wished more people would be more interested in their health.

Another woman pointed out the feeling of empowerment she experienced by being properly prepared for her appointment with the help of the *MHC*:

The health companion was really a great help to me this week. I had an appointment with my medical doctor on Monday for my... check up. I had my book with medications and all in it and added the test results from this visit. For the first time I had my questions ready and noted all we discussed. I felt so empowered to be organized and prepared for once...On Friday, I had a visit with the eye specialist -- a 3 hour drive up, a 20 minute visit followed by a 3 hour drive home. I once again was prepared and got my questions answered.

These comments on fostering a sense of empowerment, basically enhancing health literacy, and enriching client/provider interactions are heartening. However, because the anecdotal feedback on the utility of the *MHC* is limited at this time, it has encouraged us to look for

ways to use and evaluate this health record with participants in other ongoing research studies. We continue to solicit feedback on the utility of the *MHC* and glean insights from users on how to further refine this low-tech personal health record.

Discussion

The challenges of living with chronic illness will inevitably alter one's lifestyle and threaten one's emotional well-being. To ameliorate these untoward consequences, the Chronic Care Model (CCM) (Wagner et al., 2001), a comprehensive system to provide quality care for chronic health conditions, was developed to foster productive interactions between informed active individuals with chronic conditions and their health care providers. We addressed one of the CCM elements, self-management support, from the perspective of the role that a low-tech paper personal health record, *My Health Companion*®, can play in enhancing health literacy, promoting a sense of empowerment, and ultimately leading to more a positive and productive partnership between client and provider. The *MHC* can foster clearer health communication by providing a mechanism to organize, understand, and utilize the users own health information, key elements in the degree of health literacy that can be attained.

The *MHC* was shown to be useful to rural women with chronic health conditions as a means of preparing for visits with multiple health care providers and maximizing the effectiveness and satisfaction with provider encounters. From the provider's perspective, a better informed client who comes prepared for the visit with organized health information increases the probability of accurate diagnosis, development of a treatment plan, and a sense that the individual can fully participate in his/her health maintenance and treatment regimen, and, ultimately, make more informed health decisions.

While the early reports from Women to Women Project on the efficiency of the *MHC* are encouraging, more rigorous evaluation is critical. Thus, the *MHC* is being used and evaluated in several other studies with rural men and women living with chronic health conditions. In these studies, a hard copy of the instructions for the use of *MHC* has been substituted for the online version. The measurement of the impact of using the personal health record with an increased sample size will allow for more in-depth analysis and evaluation of this newly developed personal health record.

The goal of our overall program of research is to help rural dwellers more effectively manage their chronic health conditions. By developing a means for them to document key health information, it is anticipated that their health literacy will be enhanced; thus, they will have a better grasp of their own health information. Likewise, they will have the increased knowledge needed to obtain, understand, and utilize health information, make better informed health decisions, and interact more effectively with the limited health care resources generally found in rural setting. Health care providers can take the lead in encouraging their clients to use a personal health record along with offering support in its use. A more health-literate client, utilizing a personal health record, can serve as a vehicle for the establishment of more productive interactions that will achieve true client-provider partnerships in health care.

References

- AHIMA/AMIA. The value of personal health records: A joint position statement for consumers of health care. 2007 from www.ahima.org/dc/positions/documents/MicrosoftWord-AHIMA-AMIAPHRStatement-final.pdf.
- Ball MJ, Smith C, Bakalar R. Personal health records: Empowering consumers. *Journal of Healthcare Information Management*. 2007; 21(1):76-86. [PubMed: 17299929]

- Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *The Journal of the American Medical Association*. 2002; 288(19):2469–2475.
- Boodman S. A silent epidemic. 2007 from <http://www.washingtonpost.com/wpdyn/content/article/2007/02/16/AR2007021602260.html>.
- Endsley S, Kibbe D, Linares A, Colorafi K. An introduction to personal health records. 2006 from <http://www.aafp.org/fpm/20060500/57anin.html>.
- Federal Citizen Information Center. Personal health records. 2008 from <http://www.pueblo.gsa.gov/cfocus/cfphr07/focus.htm>.
- Gunning R. The Fog Index after twenty years. *Journal of Business Communication*. 1969; 6(3)
- Hill W, Weinert C, Cudney S. Influence of a computer intervention on the psychological status of chronically ill rural women: Preliminary results. *Nursing Research*. 2006; 55(1):34–42. [PubMed: 16439927]
- Isaac S, Reed H. Encyclopedia of public health: Access to health services. 2008 from <http://www.answers.com/topic/health-care>.
- Lansky, D.; Brennan, PF. Personal Health Record Track; Paper presented at the NHII Conference 04; 2004. from http://aspe.hhs.gov/sp/nhii/Conference04/personal_health_paper.pdf
- National Education Association. Building a personal health record. 2008 from <http://www.nea.org/money/pf071119.html>.
- Partnership for Clear Health Communication Steering Committee. Eradicating low health literacy: The first public health movement of the 21st century. 2003 Overview. from <http://healthpowerforminorities.org/specific/EradicatingLowHealthcareLiteracy.pdf>.
- Robert Wood Johnson Foundation. The Chronic Care Model: Model elements: Self-management support. 2003 from http://www.improvingchroniccare.org/index.php?p=Self-Management_Support&s=22.
- Seminole County Patient Safety Initiative. Improving health literacy. 2006 from http://scmsociety.typepad.com/patient_safety/health_literacy/index.htm.
- Tang P, Ash J, Bates DM, Overhage J, Sands D. Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*. 2006; 13(2):121–126. [PubMed: 16357345]
- Usingenglish.com. Fog Index. 2008 from <http://www.usingenglish.com/glossary/fog-index.html>.
- Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: Translating evidence into action. *Health Affairs*. 2001; 20(6):64–78. [PubMed: 11816692]
- Weinert C, Cudney S, Hill W. rural women, technology, and self-management of chronic illness. *Canadian Journal of Nursing Research*. 2008; 40(3):114–134. [PubMed: 18947095]
- Weinert C, Cudney S, Winters C. Social support in cyberspace: The next generation. *Computers, Informatics, Nursing*. 2005; 23(1):7–15.
- Weinert C, Whitney A, Hill W, Cudney S. Chronically ill women's views of health care. *Online Journal of Rural Nursing and Health Care*. 2006 from www.mo.org/journal/issues/vol-5/issue-2Weinert_article.htm.

Table 1**Basic Principles of a PHR**

The following PHR principles guided the development and utilization of the *MHC*:

- 1 Each person is ultimately responsible for making decision about his/her health.
 - 2 Information in the PHR should be understandable to the individual.
 - 3 Information in PHR should be accurate, reliable and complete.
 - 4 The PHR may be separate from and does not normally replace the legal medical record of any provider.
 - 5 Privacy protection of PHR data should follow the data.
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Table 2

Pfizer's Principles for Clear Communication

1	Base the content on written objectives. Explain the purpose and limit the content.
2	Involve the reader.
3	Make it easy to read.
4	Make it <i>look</i> easy.
5	Select visuals that clarify and motivate.

Table 3Contents of the *My Health Companion*©

Section Title	Section Content
Section 1. Basic Information	Demographic and health care provider information
Section 2. The Health History	Health care visits in past year, e.g., emergency department, dentist, primary care provider, etc. Chronic illnesses Past surgeries/procedures Allergies Physical limitations Past serious illnesses and/or hospitalizations History of family illnesses
Section 3. Current Health Information	How do you feel today emotionally, physically? What makes you feel better? Worse?
Section 4. Medication and Preventive care	Current medication record Immunizations Regular physical examinations
Section 5. Laboratory Test Results	Laboratory test results Laboratory test goals
Section 6. Personal Support System	Spiritual support Help with transportation Help with shopping/household responsibilities Help with children Help when I am sick Supports me by listening to my concerns
Section 7. Questions for My Health Care Provider	What is my health problem? What do I need to do? Why is it important for me to do this? When do I need to see you again? Is there anything else I need to know? Other questions I have:
Section 8. Insurance Information	Health insurance, policy #, contact Medicare, policy #, contact Vision insurance, policy #, contact Dental insurance, policy #, contact Medication insurance, policy #, contact
References and Additional Resources	http://www.pugetsoundhealthalliance.org http://www.askme3.org http://www.AHRQ.gov http://www.Safemedication.com