

Using the Personal Health Record to Improve Health Literacy: A Social Capital Perspective

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Abstract

Introduction: *The provider-patient relationship has been changed as a result of increased demands on provider's time and reimbursement methods. This has put a strain on the health education portion of physician's appointments and left many patients with a low health literacy.*

Background: *Low health literacy has implications for patient satisfaction, and outcomes. The personal health record (PHR) may be means to increase social capital in the form of provider-patient relationships and increase health literacy.*

Methods: *This research focuses on the PHR and patient health literacy. Participants were asked to complete a survey regarding their feelings toward PHRs.*

Results: *A qualitative analysis was conducted from 562 patients at a primary care physician's office. Three themes regarding patients' feelings about PHRs emerged from this study; convenience, connectivity, and literacy.*

Conclusion: *This research suggests that the PHR is an important tool for health care managers to consider when discussing patient education and literacy.*

1. Introduction

The introduction of the Personal Health Record (PHR) has allowed patients unprecedented access to their health information. This access can have both a positive and negative affect on patients' understanding of their own health. While the educated patient can utilize this information for decision making purposes, the patient without an adequate understanding of his/her own healthcare can be overwhelmed and discouraged by this information. In light of this, the need to assist patients with their own health literacy has become an unintended consequence of the digital revolution.

The health care system has its own language, environment, and process that combine to result in information overload for many to understand and functionally apply (Coulter & Ellin, 2007; Smith & Duman, 2009). The degree to which these factors can be readily understood and applied to improve health outcomes is the basis for health literacy (Coutler & Ellins, 2007; Kunter, Greenberg, Jin, & Paulsen, 2006; Smith & Duman, 2009). An individual with a high level of health literacy has the ability to gain access to, understand, and use information to promote and maintain good health (Nutbeam, 2000).

An individual with low health literacy has difficulty with the functional application of health related instructions such as taking prescribed medications, following a special diet, or completing medical forms (Lee, Arozullah, & Cho, 2004). These factors are challenging to overcome without assistance from health care professionals and highlight the importance of the provider-patient relationship in promoting health literacy.

Provider-patient relationships can be viewed in terms of social capital theory. The theory of social capital is a sociological concept that seeks to explain the relationships within and between societal organizations to produce a desired benefit. The benefits of a strong patient-provider relationship are improved health literacy, self-care, and health outcomes (Beach, Keruly, & Moore, 2006; Forrest, Shi, von Schrader, & Ng, 2002). Research shows that women with chronic illnesses who are connected to their provider demonstrate a greater sense of well-being, continuity of care, increased care options, and self-care activities (Fox & Chesla, 2008).

However, new challenges in developing these connections have arisen with the advent of managed care organizations, increased number of uninsured, cost containment efforts, and decreased provider supply (Forrest, Shi, von Schrader, & Ng, 2002). As a result of these factors, providers are spending less time with patients and utilizing the electronic medium to supplement insufficient office time for health education.

The patient-provider relationships will be examined as a type of social capital and through the social capital lens; this report will postulate that health literacy will increase with an associated increase in the provider-patient relationship. It will then use the Personal Health Record (PHR) as a vehicle to improve health literacy by enhancing the provider-patient relationship and increasing patient participation in care delivery. Qualitative research is used to illustrate patients' emotions as they consider the use of a PHR as a communication tool with their providers.

2. Background

2.1 Social Capital: Social capital embodies the idea that social networks have value (Putnam, 2000) and supports the concept that resources embedded in society enhance overall quality of life. Networks provide these resources by providing information, exerting influence, and acting as social agents (Song & Lin, 2009). Social capital is also the primary means by which an individual in a society integrates with others and in its most basic form, links an individual to society. Wan & Lin (2003) describe social capital as a "major social force" whose concepts influence peoples' health and postulate that higher social capital is associated with better access to care. The rules and norms of informal (intragroup) and formal (intergroup) relationships are also deeply imbedded in the theory of social capital and highlight the importance of the intergroup (provider-patient) relationship and its influence on the intragroup (neighborhoods, community, etc.) environment (Dasjupta & Serageldin, 2000).

Pierre Bourdieu is one theorist whose work forms the foundation of the intragroup and intergroup relationship. He defines social capital as all resources (actual and potential), related to "possession of durable networks of more or less institutionalized relationships of mutual acquaintance and recognition...(Bourdieu, 2008, p. 47)." Bourdieu states that "the social world can be represented by a space constructed on the basis of principles of differentiation or distribution constituted by a set of properties active within the social universe (Bourdieu, 1985, pp.723-724)." Relative position in the societal space is determined by economic capital, cultural capital (education, skill level, etc.), symbolic capital (prestige, reputation, etc.) and social capital (connections) (Aguilar & Sen, 2009; Bourdieu, 1985, 2008).

2.2 Field and Habitus: Critical to Bourdieu's work on social space are the notions of field and habitus. Bourdieu includes the concept of social class in fields, or how individuals are arranged in society (Aguilar & Sen, 2009). One's resources or position in society often determines the ability to make positive, healthy promoting decisions; otherwise, healthy behaviors are reduced to sheer motivation (Korp, 2008). Habitus refers to perceptions, thoughts and actions (Bourdieu, 1985) and how an individual responds to social circumstance, including life choices (Korp, 2008). It is formed through experience, position, and movement in a social world that is filtered through personal history and memory (Aguilar & Sen, 2009).

Bourdieu's concepts of field and habitus are exhibited in the provider-patient relationship. The field, the provider-patient relationship, is where power struggles occur. Habitus may reflect an individual's social orientation or experience in the relationship. It provides insight into how the individual responds in the provider-patient relationship.

In the optimal relationship (Figure 1), there is a continual flow of information and feedback in the field. The habitus is affable and reflected in patient affirmation, learning, and ability to apply health related information. The result of this open communication is an increased health literacy that is beneficial to the patient's health outcomes and social networks.

A patient's response to this "power" may also be negative. A provider's "power" as demonstrated by a provider's authority, may result in an attempt to discount the relationship, and become disengaged in the relationship. This results in missed opportunities for health education. For example, those who have low health literacy may feel dominated in the conversation and seek isolation from the health care provider.

2.3 Health Literacy: This perceived domination and resulting isolation highlights the importance of health literacy, and emphasizes the need to reverse the current trend. More than one-third of English speaking patients and one-half of Spanish speaking patients at U.S. public hospitals have low health literacy (Liechty, 2011; Marcus, 2006) and nine out of 10 adults have difficulty using "common" health information (Kunter et al., 2006). Low health literacy rates are related to poor health outcomes from improper medication compliance, lack of preventative care, and increased hospitalizations (Berkman, 2004; Paasche-Orlow, Parker, Gazmararian, Bohlman, & Rudd, 2005).

2.4 Medication compliance: It is estimated that 50% of medication regimens are adhered to correctly, and noncompliance is related to low literacy (MacLaughlin et al., 2005). This has implications for patients with comorbidities, and may increase the severity and incidence of complications. Adherence to medications can also significantly lower adverse clinical events, health care costs, hospitalizations, and emergency department visits (Pittman, Chen, & Stettin, 2010; Roebuck, Liberman, Gemmill-Toyama, & Brennan, 2011). When compared to patients who were non adherent to medications, patients who were compliant had an average annual cost savings on total health care expenditures between \$1,258 and \$7,823 (Roebuck et al., 2011).

2.5 Preventative Care: Low health literacy is also correlated with a decreased ability to prevent and manage chronic diseases (Gazmararian, Williams, Peef, & Baker, 2002) including a decreased use of preventative services such mammography, resulting in a higher incidence of advanced stages of breast cancer (Davis et al., 1996) and a decrease in self-care management of breast cancer (Williams, Baker, Honig, Lee, & Nowlan, 1998). More than 50% of cancer could be prevented if knowledge of risk factors was successfully applied and mortality could be reduced by 60% if society adhered to cancer prevention strategies (Colditz, DeJong, Hunter, Trichopoulos, & Willett, 1996).

2.6 Hospitalizations: Low health literacy has been linked to increased hospital utilization, which leads to increased health care costs (Baker, Parker, Williams, & Clark, 1998). Patients with low health literacy average 6% more hospital admissions and an associated increase length of stay (Kirsch, Jenkins, & Kolstad, 1993). Increased emergency room usage and decreased outpatient services usage for those with low health literacy suggests that these patients may use fewer outpatient services to avoid completing forms (Marcus, 2006). This funnels low literacy patients into the emergency room where someone else is asking the questions and the form is being completed on their behalf thus reducing the embarrassment associated with low literacy (Marcus, 2006). This makes the use of emergency departments more convenient for those who try to hide their inability to complete forms required for care.

2.7 Social Capital and Health Literacy: As the health care system seeks to improve health literacy, social capital concepts are foundational in understanding the provider-patient relationship. When health care providers are actively engaged, they can influence behavior and the ability of the public to properly apply health related information

The health care professionals' approach in their relationships with patients has a direct impact on their degree of educational influence. It is the responsibility of the health care professionals to recognize varying literacy levels among individuals, understand cultural barriers, and provide the appropriate level of information. Affirming patients' significance as active participants in the provider-patient relationship, has significant implications for improving health outcomes (Hibbard, Stockard, Mahoney, & Tresser, 2004; Otero-Sabogal et al., 2010). Research has demonstrated that improving health care literacy improves healthy behaviors and health status (Li-Chun, 2011).

Proactive health education programs sensitive to the needs of the population improve linkages between health literacy, knowledge, self-efficacy, physical activity, and health status. Osborn, et al (2010) suggest that health literacy affects social support and social support affects self-care management. The literature recognizes that although interests in self-care management are high, preferred methods of delivery differ among groups (Sarkar, Piette, Gonzales, & Schillinger, 2008). PHRs have the potential to improve the provider-patient relationship by enhancing communication with documentation (Kupchunas, 2007).

2.8 Personal Health Records: The concept of PHRs includes records of medications, office visits, and laboratory reports. With the advancement in technology, these records can be in an electronic format that is shared with health care providers. PHRs contain vital health information that stimulate active participation in the delivery of care and support a patient-centered approach to care (Kupchunas, 2007). Patient centered care includes increasing education in patients with chronic ailments and improves self-report of health, functional status, and satisfaction with care.

PHRs can allow the integration of appropriate intervention programs and improve overall communication between patients and providers. Health care professionals, responsible caregivers, and patients are accountable for the maintenance and understanding their own records. If low health literacy is detected, appropriate intervention can be instituted to address concerns. The PHR provides a smooth transition to self-directed record maintenance and can facilitate trans-disciplinary education (Kupchunas, 2007). This type of record maintenance improves engagement, self-management, and collaborative communication.

The majority of adult Americans (79%) believe that a PHR would provide major benefits in healthcare management (Connecting for Health, 2008). A distinct advantage of the PHR is the ability it affords the patient to be an active member of the medical team and not just a passive consumer of healthcare services. An active team member will seek the ability to understand the content of the PHR, including diseases and medications. This understanding is important in that it allows patients to recognize the benefits of access to their health information (Lober et al., 2006) including the ability to refer to treatment plans which can result in improved care and, more importantly, prevent an untoward event (The Joint Commission, 2007).

3. Materials & Methods

The goal of this research is to determine the likelihood that patients will adopt a PHR if it is provided by their practice physicians based on perceived literacy among other factors. The study used a convenience sample with primary data collection via a questionnaire. Institutional Review Board approval was obtained prior to commencement of the research. An internal medicine practice was selected to improve generalizability to other general practitioners.

3.1 Survey: The survey looked at several different areas of interest to PHR adoption, including: intention to use, usability of the PHR, usefulness of the PHR, health status and health literacy of the patient, socioeconomic status, and demographic information. A pilot study was performed to determine issues with the survey itself as well as for face validity.

All patients who presented to the office for care were invited to participate in the research which took place in November and December, 2009. A letter describing the research along with an information sheet about PHRs was provided to the patients who were willing to participate. Verbal instructions were given on how to complete the questionnaire. The questionnaire was a hard copy instrument that was completed by the patient in the office waiting room.

For this research, the free response portion of the survey was analyzed in an attempt to ascertain patient emotions about PHR use and how these relate to the concepts of social capital and health literacy. Thematic analysis was conducted by two researchers. A final code schema was attained through consensus.

4. Results

A total of 562 patients participated in the research, accounting for approximately 14% of the active practice patients. Overall, 75% of the participants indicated they would adopt the PHR. The demographic characteristics show that 79% of males and 75% of females expressed willingness to adopt the PHR. The age group between 26 and 40 years indicated an 80% willingness to adopt the PHR.

Married patients were more willing to adopt the PHR (82%) than unmarried (71%). Seventy-five percent of the patients who participated in the research were white, and 76% of those were willing to adopt the PHR.

4.1. Key Themes: Of the 562 patients who participated in the survey process, 49 wrote comments in the box provided at the end of the questionnaire. Of those, 17 comments were used for this analysis of social capital and health literacy. The three themes that emerged from the comments are: convenience, connectivity, and literacy.

4.2. Convenience: Leonard (2004) validated that patients believe if they are given access to their medical records, they will be able to manage their condition(s) at home. DeClercq et al (2003) found it was important to include patient input as they designed the system for their patients. This actually lengthened the design time but allowed the physicians to provide a user-friendly system to their patients.

A couple of patients did specifically mention the importance of the PHR being user friendly. One was particularly concerned about seniors being able to use the system. Other patients focused on the potential time savings in terms of making appointments, getting prescription refills, and remembering discharge instructions. The ability to take records to another physician for continuity of care was also appealing.

4.3. Connectivity: Continuity of care is a distinct advantage of PHRs. The PHR can provide direct and timely communication with the physician and empower the patient to be involved and participate in the decision making process about his or her health (Ball, Smith and Bakalar, 2007). One patient agreed with this point and said “I would welcome an internet health connection with my physician to enter pertinent daily conditions.” This comment relates to the Field and Habitus component of social capital theory.

It is also possible that if patients know they are being observed and monitored by their provider(s) they will be more motivated to adhere to the guidelines provided to them for health maintenance (Green, 1987). Patients may even see their providers as “guardian angels” who are looking over their shoulder (Ralston, Revere, Robins, & Goldberg, 2004). One patient who appreciates this type of supervision said “This practice is the greatest – they take the time to assess, treat and give feedback. Personal kindness means a lot.” Another patient who is not interested in using a PHR but does want to remain connected said this: “Perhaps if I was a lot younger I would do this, but no interest at this time. Also, let’s not lose the personal touch.” Another patient commented on the importance of the relationship between the doctor and patient stating, “Info is always better when it comes straight from the doc.”

Therefore, this research shows that relationships and social capital can play a part in how a patient feels about the usability of a PHR. While a patient may appreciate the ability to communicate with the physician, often it comes down to “it is a great way for busy people who are healthy to not have to come to the office where there are ill people, exposing ourselves to illness.” However, one patient who “likes the idea that I can obtain my medical information without calling the doctor’s office” prefers to follow up with the physician.

4.4. Literacy: Physician-patient communication and increased decision-making involvement by the patient are vital components of a successful self-management program and improved patient outcomes (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). Many people find that the ability to participate in the formation and ongoing supervision of their own care improves their satisfaction and, actually motivates them to follow instructions and treatment plans. Ongoing research at the Cleveland Clinic confirms that patients like the flexibility of reporting blood pressure measurements when it is convenient to their schedule and based on their availability and need (Moore, 2009). Maly, Bourque, and Engelhardt (1999) concur, stating that communication, specifically information exchange, improves the health of the patient as well as the patient’s satisfaction with care.

Patients are often aware of their shortcomings when it comes to health literacy and this may impact their willingness to use a PHR. One patient expressed the need for a 24 hour hotline to answer questions that arise from the increased information available to the patient. Another patient said, “I think this is a great idea but some people, me included, will need some cheat sheets or workshops to feel comfortable.” Others realize they will need guidance from the physician, stating “The internet is a good source to find information pertaining to certain symptoms you may have. However, I would never rely completely on the answers. I would follow up with my physician/specialist.” Yet another patient, who has been an RN for over 30 years states, “This is a great idea! I would love it!”

Health literacy is not the only concern with PHRs. Patients must also be able to use a computer and navigate through the internet. Social capital can play a role for these patients as well because they may have to rely on a friend or family member to look things up for them. However, it is encouraging to note that there are patients willing to play the role of the champion user. During the pilot study, one patient commented, “I can teach software use.” This patient was in the oldest age category (71 years and older) and would make an excellent champion for other senior citizens. Kim et al. (2005) also noted the importance of “champion residents” in improving PHR adoption in their community of primarily disabled and elderly residents. These experiences indicate that improved PHR usage may occur if a few patients will act as change agents to promote the PHR to other patients.

5. Discussion

A number of factors have contributed to a decrease in social capital and specifically, the provider-patient relationship. This reduction has tasked primary care physicians with the unenviable task of providing patient education through alternative means and put the burden on patients to understand their health and preventative care. The PHR can achieve these means, but only if the patient has a sufficient health literacy and a willingness to engage technology.

Health literacy has been shown to be an important vehicle for improving the quality of overall public health. Health care providers play a vital role in encouraging and educating patients to take an active interest in their own health status. From a social capital framework, as presented by Bourdieu and Putnam, the health care provider plays a significant role in health education. PHRs can be useful to increase health information availability, convenience, and connectivity to providers. PHRs can be used to facilitate active seeking and functional application of health information to increase health literacy and quality health outcomes.

Three key areas (convenience, connectivity, and literacy) are distinct advantages of PHR that are validated by study participants. Applying the advantages of PHR to current medical needs is critical for successful and functional application of this tool. Longo et al., (2010) suggest that behavioral changes are favorable when the change has current relevance and applicability.

PHRs encourage active engagement in self-care management and communication with health care providers. Through ongoing communication, PHR can form the basis for which a social structure is built to improve health literacy. This study supports prior research that patients have a preference for information that is accessible and easy to understand (Longo et al., 2010). Information exchange between patient and provider improves the health of the patient and patient satisfaction with care, thereby improving social capital (Maly et al., 1999). Health literacy and social capital can improve concomitantly through the purposeful application of PHR.

The convenience sampling methodology presents a challenge to the study. The voluntary nature of the study may characteristically exclude important considerations, lending itself to selection bias. Nonrandom incomplete surveys and patient honesty may influence the validity and reliability of the collected data as well. Also, this study was limited to one medical practice which currently uses EMR (but with no PHR capability), therefore this study should be replicated with an increased sample size including facilities that do and do not currently incorporate technology into their practice to increase external validity. Participants' prior experience with technology may bias their perception and adoption of PHR.

This research suggests that health care managers adopt policies that encourage patient control and autonomy. Health care organizations who implement PHR may imagine it as a personal resource to encourage health care communication and strengthen social capital. Strategies may also include educational programs for individuals who lack adequate skills to functionally use PHR. As the implementation of technology infiltrates the health care society, the impact of health literacy and computer literacy become critical to promoting patient centered care, especially among the geriatric population. It is suggested that healthcare managers consider policies and educational tools aimed at increasing health and technology literacy in tandem for overall health promotion and disease prevention.

Future research in this area should address barriers to adopt PHR among patients and more specifically, the effect that this form of social capital has on health outcomes.

The PHR should be examined as a proactive, cost containment strategy to reduce hospitalizations and adverse clinical events by providing educational outreach on a continual basis. Other opportunities for research include a longitudinal analysis of the influence of PHRs on health literacy and health status.

6. Conclusion

Low health literacy is a silent epidemic that has challenged the health care system. The challenges associated with inadequate health education can contribute to poor outcomes in quality, access, and cost. This highlights two critical issues: how society provides health related information and the ability of the public to receive, process, and apply the information. Increasing the efficiency of transmitting health information and ensuring functional application of the information is critical for improved community welfare.

This adds a significant responsibility for health care providers to effect change among patients. Providers need to take a proactive role in patient education to improve public health. With the current challenges facing the health care system, creative avenues need to be explored to alleviate health literacy while decreasing the burdens placed on providers in public health promotion. Personal health records (PHR) may provide a viable option for patients to be actively engaged in their own care. There is also the potential to enhance health literacy through the provider-patient relationship. By re-establishing the unique role in promoting public health education, the health care system can create positive, health related behavioral changes in aggregate communities.

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Table 1: Demographic Characteristics

Demographic	Category	Intend to adopt %	Do not intend to adopt %
Gender	Male	79	21
	Female	75	25
Age	25 years of age or younger	70	30
	26-40 years of age	80	20
	41-55 years of age	77	23
	56-70 years of age	73	27
	71 years or older	67	33
Marital status	Single, never married	66	34
	Partnered	79	21
	Married	82	18
	Separated	74	26
	Divorced	74	26
Race/ethnicity	Widowed	67	33
	American Indian or Alaska Native	50	50
	Asian	80	20
	Black or African American	75	25
	Hispanic or Latino	71	29
	White	76	24

Figure 1

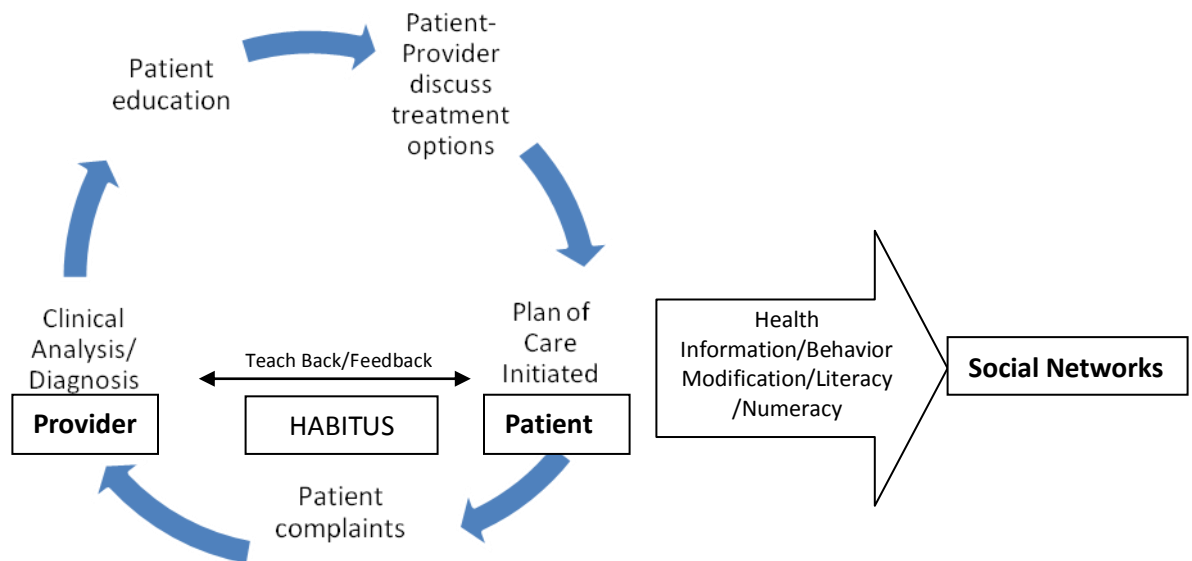


Figure 1 Field and Habitus. The Field is the provider-patient relationship. The Habitus is the patients’ response to the provider. This figure depicts the flow of information in an optimal provider-physician relationship, as health literacy increases, prior to transferring information to social networks.