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Clinical Methods

Developing a personal health record self-efficacy tool

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Abstract The purpose of this preliminary work was to develop a new short tool to assess personal health records (PHRs) self-efficacy. Prior work had found 4 distinct skills related to creating, updating, tracking symptoms, and sharing information with health care providers using PHR. Although PHRs have great promise, their uptake has been rather limited, especially in economically limited populations. A convenience sample of community-living persons with HIV/AIDS (N = 100) was asked to complete the new tool along with other self-efficacy measures. Preliminary work indicated more confidence about paper-based PHRs compared with computer-based PHRs. The paper-based subscale was significantly correlated to chronic illness and HIV treatment self-efficacy scales as expected, but there were no relationships for the computer-based subscale. This simple screening tool could identify interested clients and their preference either for a paper-based or computer-based PHR. Further research is needed with larger sample sizes and different chronically ill populations to further explore the psychometrics of the instrument.

1. Introduction

It is increasingly important for consumers, especially those who are chronically ill, to be actively involved in their health care. Health care empowerment can be characterized as both a process and state of participation that is engaged, informed, collaborative, committed, and tolerant of uncertainty related to health care issues (Johnson, 2011). The nurse can facilitate this process by teaching and enabling self-sufficiency by showing individuals how to improve their health literacy skills and use health-enabling technologies (Weaver & Zielstorff, 2011). Use of a personal health record (PHR) may increase health-related self-management skills and result in a more informed, empowered consumer. The general aim of a PHR is to increase an individual's access to and sense of ownership over personal health care information (Wynia & Dunn, 2010) over a lifetime (Oftedahl & Marshall, 2010). While some authors argue that PHR are software applications (Reti, Feldman, Ross, & Safran, 2010), others suggest that a PHR can either be computer based or paper based (Jones, Shipman, Plaut, & Selden, 2010).

With the advent of highly effective medications to treat HIV infection, HIV/AIDS has evolved from a terminal to a chronic illness that requires daily self-care monitoring and periodic interactions with different health care providers. Economic issues are shortening the time available for those interactions, and the visit needs to be framed in ways that maximizes sharing information and focused outcomes. Although not all patients prefer to share in the responsibility of making health care decisions, decision-making tools can increase patients' knowledge about their illness and reduce decisional conflict (Patel & Bakken, 2010), and a PHR could

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promote shared decision making. HIV/AIDS has greatly impacted sexual and racial/ethnic minorities who are at risk for lower health literacy because of defects in educational systems and marginalization. Medicaid, the U.S. government insurance program for persons with low income, accounts for approximately half of federal spending on HIV/AIDS care, and people with HIV are three to four times more likely to be covered with Medicaid than the U.S. population overall (Kaiser Fact Sheet, 2009). The digital divide has been associated with disparities related to race, economics, age, and education, and use of a computer-based PHR may increase disparities in marginalized populations (Oftedahl & Marshall, 2010). Although there is widespread acceptance for the value of a PHR, not all consumers, including those who are chronically ill, will want to create and maintain one. Google announced that they were retiring the Google Health program on January 1, 2012 because they have not found a way to translate limited usage into widespread adoption in the daily health routines of millions of people. Yamin et al. (2011) found that racial and ethnic minorities were far less likely to adopt a computer-based PHR to access and coordinate their health information.

There may be two interacting factors impacting adoption of a computer-based PHR—shared decision-making preference and computer literacy. Patel and Bakken (2010) found that Hispanics had a higher preference for a more passive role in decision making on the Control Preferences Scale and that participants being treated for anxiety and depression preferred more involvement in mental health decision making versus general health decision making. Kumar et al. (2010) found that 72% of an HIV positive sample ($n = 314$) preferred shared decision making with the health care provider, whereas 23% preferred that the provider make decisions. These findings support Beach, Duggan, and Moore's (2007) earlier work with clients who are HIV positive, which found that 63% preferred shared decision making and 23% preferred that the provider make all decisions.

Although PHR can either be paper based or computer based, many proponents of PHR favor computer-based platforms, especially those that interface with the electronic health record (EHR). But some consumers may feel overwhelmed by the prospect of keeping their health-related information in an organized and accurate record and paralyzed by the thought that they need to use the computer in order to achieve that goal. Kelso and Walker (2009) asked a convenience sample ($N = 124$) of primarily Caucasian, married, female, insured, college-educated, and employed persons living in Indiana about their perceived likelihood that they would complete a paper-based PHR and found that more than 66% thought that completing a PHR would be difficult. That perception of difficulty might be even greater for consumers with minimal computer skills if the only option for a PHR was a computer-based system. Yamin et al. (2011) studied adopters and nonadopters of a computer-based PHR provided by Partners HealthCare in Boston and found that the likelihood of adoption was lower among all racial and ethnic minorities with the most pronounced effect in Blacks.

Social cognitive theory proposes that triadic reciprocal causation explains the relationships between three classes of determinants—behavior, cognitive and other personal factors, and environmental influences (Fig. 1; Bandura, 1986). Perceived self-efficacy is concerned with an individual's belief in his or her capacity to perform a specific behavior (Bandura, 2006). Health literacy, as a cognitive or other

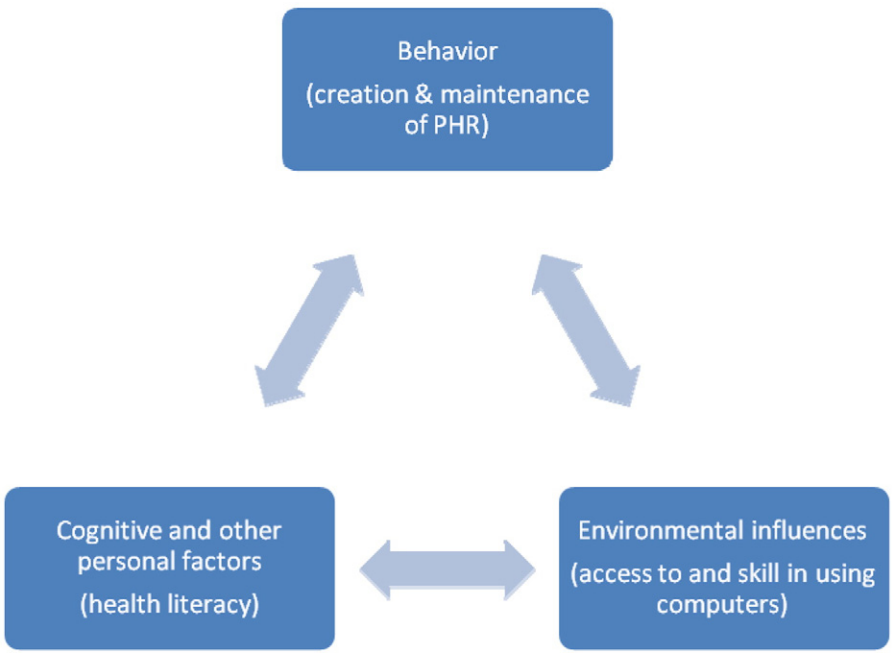

Fig. 1. Triadic reciprocal causation (Bandura, 1986) and PHR self-efficacy.

personal determinant, may impact on creation of a PHR. Environmental influences are particularly important to consider in the creation of a PHR because it can either be paper based or computer based, and access and skill in using computers can vary greatly. According to self-efficacy theory, there is no global measure of self-efficacy, but rather, scales of perceived self-efficacy need to be tailored to the particular domain of functioning that is of interest. The purpose of this study was to pilot a theory-based questionnaire about PHR self-efficacy with a chronically ill population. Although many health-related self-efficacy scales exist, none specifically assessed self-efficacy about PHR. This PHR self-efficacy could be used to identify consumers who are interested in exploring how to create and maintain a PHR.

2. Methods

2.1. Ethical considerations

The study protocol was approved by the institutional review boards at Hunter College and the community-based organization serving people with HIV/AIDS. All participants gave written informed consent.

2.2. Instruments

2.2.1. The PHR self-efficacy tool

In developing a new instrument, Bandura (2006) suggested that items should (a) be phrased in terms of "can do" rather than "will do" because "can" is a judgment of capability compared with "will," is a statement of intention; (b) measure the respondent's perception of their "confidence"; and (c) use a 0- to 100-point scale. The 9-item PHR self-efficacy tool asked "How confident are you that you can…" on a 0- to 100-point scale that ranged in 10-unit intervals from 0 (*not at all confident*) through intermediate degrees of assurance, 50 (*moderately confident*) to complete assurance, and 100 (*totally confident*).

Kelso and Walker (2009) gave members of the general public (N = 124) who were living in Indiana a 21-question survey about the likelihood of completing a PHR. Their survey consisted of open-ended and Likert-type questions and was based on the PHR created by the American Health Information Management Association. In further conversation with Kelso and Walker (2009), she identified that four distinct skills related to PHR emerged: (a) creating a PHR, (b) regularly updating a PHR, (c) accurately tracking symptoms and healthy behaviors, and (d) sharing information with health care providers in PHR. One item on the new instrument being described in this article was created to address each of these different skills identified by Kelso. The final 9-item instrument (Table 1) has one overall item related to perceived confidence in creating a PHR and then two subscales—one related to a paper-based PHR and the other related to a computer-based PHR with four items assessing the four skills on each subscale. Because one of the purposes of the PHR self-efficacy scale is to identify patients who are interested in creating a PHR, a shorter questionnaire that could be completed while waiting for the visit with the health care provider was desired (L. Kelso, personal communication, October 30, 2009).

Because the PHR is a relatively new tool, respondents were first given a description of a PHR: The PHR is a tool that you can use to collect, track, and share past and current information about your health. Medical records and your PHR are not the same thing. Medical records contain information about your health compiled and maintained by each of your health care providers. A PHR is information about your health and is compiled and maintained by you. PHR can either be created using a computer and the Internet or on paper. Respondents were also instructed with the following: "This questionnaire is designed to help us gain a better understanding of the kinds of things that persons who

Table 1
PHR self-efficacy scale (N = 100)

Concept	Item	*M*	*SD*
General PHR self-efficacy	1. How confident are you that you can create a PHR?	73.20	26.24
Self-efficacy for paper-based PHR	2. How confident are you that you can create a paper-based PHR?	73	26.64
	3. How confident are you that you can regularly update a paper-based PHR?	75.25	25.08
	4. How confident are you that you will accurately track your symptoms and healthy behaviors in a paper-based PHR?	73.64	24.63
	5. How confident are you that you will share information using the paper-based PHR when you visit your health care provider?	75.29	25.52
Self-efficacy for computer-based PHR	6. How confident are you that you can create a computer-based PHR using programs such as Google Health?	65.65	31.43
	7. How confident are you that you can update a computer-based PHR?	65.90	31.91
	8. How confident are you that you will accurately track your symptoms and healthy behaviors in a computer-based PHR?	66.50	30.76
	9. How confident are you that you will share information in the computer-based PHR with your health care provider?	67	31.47

Note. Range for all items: 0–100.

are HIV positive may experience because they create/maintain and use either paper-based or computer-based PHRs. Please rate by circling the appropriate number, your degree of confidence, and how certain you are that you can do the things discussed below. Your answers will be kept strictly confidential, and you will not be identified by name."

2.2.2. HIV treatment adherence self-efficacy scale

Adherence self-efficacy or confidence in one's ability to comply with a treatment plan has been consistently linked to adherence over time. The HIV-adherence self-efficacy scale (ASES) assesses confidence to carry out behaviors related to adhering to treatment plans including medication regimens and following plans for nutrition, exercise, and other health-related behaviors (Johnson et al., 2007). Higher HIV-ASES scores have been related to lower depression, greater problem-solving skills, social support, and general coping self-efficacy in two studies of 3,112 persons who are HIV positive. The 12 items were scored on a 1 (*not at all confident*) to 10 (*totally confident*) scale. Reliability for this sample (n = 68 to 72) was computed as .95.

2.2.3. Self-efficacy for managing chronic disease 6-item scale

This 6-item scale (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001) assesses self-efficacy related to managing a chronic disease; items are rated on a 1–10 scale, where 1 = *not at all confident* and 10 = *totally confident*; the final score is calculated as the mean of the six items, and a higher score indicates more self-efficacy. The items were modified to refer specifically to HIV rather than a global chronic disease. To illustrate, Item 1 on Lorig's scale reads: "How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?" while these participants were asked: How confident are you that you can keep the fatigue caused by your HIV from interfering with the things you want to do? According to the Web site, the instrument was tested with 605 persons who are chronically ill and yielded a mean of 5.17 (SD = 2.2) with a .91 reliability. In this sample (n = 68 to 72), the reliability was calculated as .93.

2.2.4. Self-efficacy for condom use (using condoms)

The condom use self-efficacy instrument contains nine items, modified from the original 14-item scale used in the U.S. Navy (Norris, Phillips, & Grady, 2007). Each item describes a skill related to a particular domain, with increasing degrees of challenge associated with using a condom such as when using alcohol, when the partner is resisting condom use, etc. where appropriate (alcohol use, resist partner, etc.). A 5-point scale indicating how confident the respondent was of his or her ability to perform the behavior ("absolutely sure I cannot" to "absolutely sure I can" and a "refuse to answer" option were offered for each item). Cronbach's alpha of the original total scale is .93. Reliability and validity of the original scale were evaluated and reported (Norris et al., 2007). In this sample (n = 68 to 72), the reliability was also calculated as .93.

2.2.5. Sociodemographic and HIV-related items

Participants were asked a number of items including about their age, race/ethnicity, income adequacy, and HIV-related items.

2.3. Sample/Setting

A convenience sample of persons who are HIV positive (N = 100), served by a community-based organization, participated. Table 2 presents sample characteristics. The average respondent was male, African American/Black, 48 years old, high school or less educated, has barely adequate income, unemployed (88%), infected through male/male sexual transmission, diagnosed with AIDS (56%), and taking antiretroviral medications (88%). The Momentum AIDS Project's congregate meal and pantry service attracts the hardest-to-reach individuals with HIV/AIDS. The comprehensive team of nurses, nutritionists, social workers, chaplains, and other specialists engage more than 3,000 low-income individuals with HIV/AIDS every year during meals and educate, counsel, and link them to primary health care, mental health and substance abuse treatment, housing, and other essential services.

2.4. Procedure

Recruitment flyers were posted during the regular operating hours of the community-based organization. The

Table 2
Sample characteristics (N = 100)

Sample characteristics	
Gender	
Male	94
Female	06
Age, years	
M (SD)	48.5 (8.2)
Range	27–69
Race/Ethnicity	
Asian/Pacific Islander	07
African American/Black	51
Hispanic/Latino	34
Native American	01
White/Anglo	04
Other	03
Education levels	
11th grade or less	21
High School/General education development	45
2-year college	25
4-year college and higher	09
Income adequacy	
Totally inadequate	17
Barely adequate	58
Enough	23
HIV-related risk behaviors (could check more than one risk)	
men who have sex with men transmission	55
Heterosexual transmission	35
Injecting drug use	13
Other	13

Note. Because of missing data, not all results add up to 100.

research assistant obtained written informed consent and assisted participants in completing the instrument packet as requested. All data were collected through self-report. At the completion of data collection, participants were given a $10 MetroCard for use in the New York City public transportation system. All data were collected during the fall of 2010.

3. Results

SPSS (Chicago, IL) and SAS (Cary, NC) programs were used to compute the data.

3.1. The PHR self-efficacy tool

The range of scores on each of the nine items was from 0 to 100 with a mean score of 73 (SD = 26.6) on the four paper-based items and a mean score of 65 (SD = 31.4) on the four computer-based items. A paired sample t test was computed between the means on the two 4-item subscales of the PHR tool, and there was a significant difference between the mean on the paper-based subscale and the computer-based subscale (t = 2.524, df = 99, p = .013). The paper-based PHR self-efficacy mean was significantly higher than the computer-based PHR self-efficacy.

We now turn our attention to providing a basic psychometric analysis. Because the sample size is modest, more advanced procedures such as factor analysis or item response theory are not generally recommended (Bartholomew & Knott, 1999). Therefore, we employ Cronbach's alpha, descriptive statistics, and correlation as methods that rely on weaker assumptions. For reasons we lay out below, the analysis given here involves some additional checking to determine which respondents give believable scale values. The general logic behind scale analysis procedures, such as Cronbach's alpha or, indeed, more sophisticated measurement models such as item response theory, is laid out clearly by Streiner and Norman (2008, Chapter 8). In particular, they note that it is possible to have a very high reliability coefficient when the logic of the reliability coefficient is not applicable. In particular, reliability can be high when there are conceptually distinct blocks of items that are strongly correlated but are weakly correlated across blocks. These nine items include a general self-efficacy item (Item 1) and two blocks of items—one relating to a paper-based PHR (Items 2–5) and the other relating to a computer-based PHR (Items 6–9). Thus, there is good reason to suppose that a global scale score here may not be appropriate based on the item content.

Reliability can also be inflated by other nuisance effects and response biases. In the case of self-efficacy scales, a halo effect is of particular importance. In this case, the respondents do not respond to the item content but, instead, make a global evaluation. Clearly, there appears to be a halo effect in the raw data because 28 respondents give the same response to all nine items and a relatively large number of respondents gave values that were similar. To examine this, we computed the within-person mean and standard deviation. A within-person standard deviation equal to zero implies that a respondent was totally consistent in their responses, whatever value they happened to give. For instance, a respondent who gave 100% to all nine items would have a within-person standard deviation of 0, as would someone who gave all 0%. Of the respondents with 0 within-person standard deviation, 13 responded that they were 100% confident. This may reflect overconfidence or may be accurate on the part of some respondents who may have already created a PHR. Other halo responders generally gave values indicative of overconfidence, but three said they were 0% confident. These kinds of extreme response style biases tend to boost measured reliability, artificially, because they inflate the inter-item correlations. We removed these respondents from subsequent calculations, leaving 72 respondents with complete data that do not provide "halo" responses. The correlations with the halo responders included are approximately 40% higher than those given below. It is also important to check data for gross violations of the normality assumption in the remaining 72 respondents. We used normal quantile plots on each variable to do this. The only real observed issue is the presence of a ceiling/overconfidence because there is an excess of respondents giving values of 100, showing some negative skew for each variable. This is not unusual in such confidence ratings and should not prove to be a substantial threat to subsequent analysis.

We had initially planned to compute a factor analysis. Because of the smaller sample size (n = 72), we decided to leave that analysis for future testing of the tool because the likelihood of a factor structure replicating is at least partially a function of the sample size and factor patterns emerging from smaller samples are less stable (DeVellis, 2012, 156). Bartholomew and Knott (1999) note that the risk of an improper solution with a uniqueness of one appearing is particularly high for small samples, and indeed, this is the case when one runs factor analysis on the subsample of 72.

The structure of the scale itself suggests that there may be qualitative differences among the blocks of items consistent with item wording. The correlation matrix given below (Table 3) shows the inter-item correlations among blocks of items. There are several notable patterns. The general PHR self-efficacy item (Item 1) correlates strongly with those relating to the paper-based PHR (Items 2–5) but has low correlation with those relating to the computer-based PHR (Items 6–9). This pattern is largely maintained between the paper and computer record blocks, respectively. Within each block, the correlations are generally fairly high. This suggests that it does not make sense to aggregate self-efficacy overall but that there are two relevant subscales—one relating to the paper-based PHR (which seems to overlap with general self-efficacy) and one relating to the computer-based PHR. This is not surprising given the item content. Coefficient alpha based on these 72 respondents for Subscale 1 (paper record) is .87 and, for Subscale 2 (computer record) .94.

Table 3
Means, standard deviations, and inter-item correlations for respondents ($N = 72$) giving non-halo responses

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9
Item 1	1.00								
Item 2	0.85	1.00							
Item 3	0.78	0.86	1.00						
Item 4	0.66	0.69	0.61	1.00					
Item 5	0.54	0.48	0.43	0.75	1.00				
Item 6	0.21	0.23	0.24	0.37	0.39	1.00			
Item 7	0.24	0.27	0.30	0.42	0.42	0.95	1.00		
Item 8	0.22	0.23	0.22	0.45	0.44	0.81	0.87	1.00	
Item 9	0.26	0.24	0.22	0.48	0.60	0.69	0.72	0.77	1.00
M	71.13	70.70	73.80	71.55	74.21	60.49	60.99	61.83	62.39
SD	23.81	24.46	22.06	21.15	22.79	30.22	30.94	29.39	30.59

It is still not clear that we have screened the data for all halo effect responses because we adopted a relatively stringent definition for a clear halo effect of a within-person standard deviation of 0 to preserve as many responses as possible. To assess that, we recomputed alpha but varied the cutoff of within-person standard deviation. A more stringent threshold of 10 for Subscale 1 causes it to drop to 0.78 and to 0.87 for Subscale 2. Varying the threshold does not seem to matter much past that.

3.2. Concurrent validity between self-efficacy scales

Based on the above findings, correlations were run for the 72 participants to determine concurrent validity between the PHR self-efficacy scale and other self-efficacy scales. Two-tailed Pearson product–moment correlations were computed. As can be seen on Table 4, there were significant correlations between the two subscales of the PHR self-efficacy scales ($r = .40$, $p = .000$). There was a significant correlation between the PHR paper-based subscale and adherence self-efficacy ($r = .30$, $p = .01$) and significant relationship between chronic disease self-efficacy and the paper-based PHR self-efficacy scale ($r = .23$, $p = .04$). There was no relationship between condom self-efficacy and paper-based PHR self-efficacy ($r = -.06$, $p = .617$). None of the self-efficacy scales were correlated with the computer-based PHR self-efficacy scale.

4. Discussion and conclusion

Beginning development of the PHR self-efficacy tool points to two subscales: the first or general item groups with the four items related to creating, updating, accurately tracking, and sharing information using a paper-based PHR (five items), whereas the second subscale relates to those skills associated with the computer-based PHR (four items). The triadic reciprocal causation of the three classes of determinants proposed by social cognitive theory is cognitive and other personal factors, environmental influences, and behavior. The tool was able to distinguish between self-efficacy related to creating a paper-based or computer-based PHR, which may relate more to the health literacy and other cognitive determinants associated with the individual. This differentiation might also relate to environmental determinants because access to and skill in using computers may vary greatly for persons who are chronically ill, especially those with low income. Although many libraries offer computer access, there are privacy issues with loading confidential health-related information on publicly accessible computers. Although there are many user-friendly cell phone-based applications, the monthly carrying charge to access the Internet through those cell phones may prove prohibitively expensive for persons living on fixed incomes. Approximately 75% of the sample felt confident to create and use a paper-based PHR, but policy issues remain concerning strategies and reimbursement to health care providers for visits to assist clients to organize their past and current health records.

The general paper-based subscale of the PHR tool correlates well with other indices of chronic illness self-efficacy as expected. An informed, activated chronically ill client would be expected to be interested in organizing and updating the health history so that the most appropriate interventions could be suggested by the health care provider.

Table 4
Pearson product–moment correlations between PHR, adherence, chronic disease, and condom self-efficacy scales ($N = 68$ to 72)

	Paper-based PHR	Computer-based PHR	Adherence self-efficacy	Chronic disease self-efficacy	Condom self-efficacy
Paper-based PHR	1.00				
Computer-based PHR	**.40.000**	1.00			
Adherence self-efficacy	**.30.011**	.08.468	1.00		
Chronic disease self-efficacy	**.23.045**	.13.251	**.63.000**	1.00	
Condom self-efficacy	−.06.617	.035.776	**.25.037**	**.23.049**	1.00

Note. Significant results are bolded.

The higher correlation between adherence self-efficacy and the paper-based PHR self-efficacy would also be expected because more adherent clients would be more informed about the treatment plans and attempt to organize the data in a meaningful way, which is the overall goal of the PHR. It is also not surprising that there is no relationship between condom self-efficacy and the paper-based PHR because condoms are used to prevent infection and the PHR seems most appropriate for persons who are chronically ill who are dealing with self-care, symptom management challenges on a regular basis.

A 9-item PHR self-efficacy tool was developed to identify consumers interested in creating a PHR. The paper-based PHR subscale operated as desired in a low-literacy, minority population living with HIV/AIDS, whereas the computer-based subscale was not as robust. Use of the 9-item scale with a higher literacy population might yield different results because most of the research is finding that higher educated, White persons living with HIV/AIDS are more likely to use a computer-based PHR. Health disparities can be heightened if tools are not adapted to meet the needs of the population and educational interventions developed to meet the unique needs of different subgroups. These results identify two areas for intervention: (a) skills required to create a PHR and (b) computer-related skills to organize health-related information into a PHR using prepacked computer systems. Future research includes further psychometric testing of the tool with a larger sample, and this testing would include test–retest reliability and careful analysis of the factor structure.

The 9-item scale can be easily used as a screening tool in clinical settings to raise awareness about PHR and identify preferences for paper-based or computer-based systems. Preference for a paper-based system might point to an underlying computer literacy deficit, which could be addressed. PHRs are a relatively new tool that could increase patient empowerment by organizing health-related information in a meaningful way and could promote shared decision making between consumers and health care providers. Consistent with self-efficacy theory, this tool is specific to the skills of creating, updating, accurately tracking, and sharing information either about a paper-based or computer-based PHR.

Clinicians could post information about PHR in primary care settings and encourage clients to ask for more information during the visit with the health care provider. Clients interested in a paper-based system could be further assessed for computer literacy skills and, if lacking, referred to informational sessions. Often, public libraries and senior centers have computer literacy courses, and nurses could partner with these community-based settings to offer classes about PHR. These interventions could be integrated into the community/public health nursing curriculum clinical activities for undergraduate students, whereas graduate community/public health nursing students could develop and evaluate programs to target specific communities and tailor interventions to meet unique needs. Because a PHR that interfaces with the EHR is one major goal, assisting consumers to remove the initial uptake barriers in creating a PHR should facilitate more widespread adoption of this potentially useful consumer empowerment tool.

We described beginning work on the development of a PHR self-efficacy tool and found that the tool has potential for use in clinical settings because it is short and distinguishes between paper-based and computer-based self-efficacy along with general confidence in creating a PHR. A search of the literature did not identify any other PHR self-efficacy tools; not surprising because PHRs are a relatively new tool to assist consumers in managing their health-related information.

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