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Key words: health care proxy, patient portal, patient-computer interview, advance care planning.

Word count: 3781
Abstract

Objective
Health care proxy (HCP) documentation is suboptimal. To improve rates of proxy selection and documentation, we sought to develop and evaluate a web-based interview to guide patients in their selection, and to capture their choices in their electronic health record (EHR).

Methods
We developed and implemented a HCP interview within the patient portal of a large academic health system. We analyzed the experience, together with demographic and clinical factors, of the first 200 patients who used the portal to complete the interview. We invited users to comment about their experience and analyzed their comments using established qualitative methods.

Results
From January 20, 2015 to March 13, 2015, 139 of the 200 patients who completed the interview submitted their health care proxy information for their clinician to review in the EHR. These patients had a median age of 57 years (IQR 45-67) and most were healthy. The 99 patients who did not previously have health care proxy information in their electronic health record were more likely to complete and then submit their information than the 101 patients who previously had a proxy in their health record (Odds Ratio 2.4,
P= 0.005). Qualitative analysis identified several ways in which the portal-based interview reminded, encouraged, and facilitated patients to complete their HCP.

**Discussion and conclusion**

Patients found our online interview convenient and helpful in facilitating selection and documentation of an HCP. Our study demonstrates that a web-based interview to collect and share a patient’s HCP information is both feasible and useful.
BACKGROUND AND SIGNIFICANCE

Written advance directives (AD) in the form of living wills and health care proxies (HCP), allow patients to formalize their wishes for future health care before they reach decisional incapacity. Having an advance directive in place increases the likelihood of a patient's wishes being honored, often resulting in less aggressive care, lower cost(1) and less likelihood of death in the hospital. (2) Though studies have shown an increasing upward trend for patients having advance directives(3,4), the rate of implementation is still suboptimal(5).

The Patient Self-Determination Act (PSDA) of 1990 (6) and the Joint Commission on Accreditation of Healthcare Organizations have set requirements regarding advance directives(7). Despite policy work and clinicians’ understanding of the importance of patients having an advance directive, clinicians are often unable to spend adequate time with patients to guide them through advance care planning due to time and cost constraints. (8) Additionally, all parties may find these conversations uncomfortable, which further impedes their occurrence. A recent study of Medicare beneficiaries showed that less than 1% of study participants had patient-physician end of life discussions during routine care. (9)

Prior work has looked into improving the completeness of HCP documentation. (10–13) Reminders for patients about advanced care planning, typically through mailings, have
been shown to be more effective than reminders to clinicians. (7,8) Computers have also been used to help patients navigate the process with good effect. (14,15) Online resources do exist to enable patients to document their health care proxy and advance directives and some offer to share this information with patients’ clinicians – many for a fee. (12,13) However, we have yet to find a report of a health care system with advance care planning tools that are integrated with an electronic health record system.

Computer–based medical interviewing was first reported in 1966 (16) and studies over the years have demonstrated the potential of patient-computer dialogue to obtain comprehensive, accurate medical histories that are well received by patients and clinicians. (17–21) Studies have also demonstrated that computer-based interviews can sometimes obtain sensitive, even potentially embarrassing information that might not otherwise have been obtained by a clinician interviewer. (17,22–26)

Patient access to effective and tailored patient education and electronic patient-provider communication tools can lead to improved patient-centered care. (27–29) Patient portals, are secure web sites that enable patients to connect with their clinicians and their medical center’s electronic health record system in a protected manner, and are good platforms for patient engagement tools. (30) We report here our study of a HCP interview for use by patients over our patient portal, PatientSite, to assign a proxy for themselves and, when they wish to do so, to submit and thereby share their proxy information with their clinicians who can then integrate this information into the patients’ electronic health records.
METHODS

Setting

This study took place at Beth Israel Deaconess Medical Center (BIDMC), a 649 bed urban, academic medical center affiliated with Harvard Medical School. BIDMC has 2,353 staff physicians and cared for more than 269,000 patients in 2014 at the main campus in Boston, MA. BIDMC has a rich history in clinical computing, having had one of the early hospital-wide clinical computing systems (31), with a home-grown electronic health record (webOMR) (32) and patient portal (PatientSite). (33) BIDMC is also one of the sponsor hospitals supporting the Conversation Project (34) with hospital wide initiative to help patients become “conversation ready” to share their care wishes with their loved ones.

BIDMC has been providing patients, 18 years and older, with access to PatientSite, since 2000. Communication over PatientSite enables patients to exchange messages with their clinicians, schedule appointments, request managed care referrals, refill prescriptions, view laboratory results, and view clinicians’ notes. (35,36) In addition PatientSite has provisions to conduct patient interviews. (20) As of February 2015, PatientSite had approximately 85,000 active users, with an average of 3,067 patients using it each day. The mean age of PatientSite users is 48.1 years and 62 percent of the users are women.
Health care proxy documentation process prior to availability of the health care proxy interview

Prior to the availability of the HCP interview, patients at BIDMC provided their HCP information either in person or by mail. During an ambulatory clinic visit, a non-interrupting notification would display to the medical assistant and clinician if the patient was older than 65 years and did not have HCP information in his or her electronic health record. The medical assistant would typically ask the patient for the information, or provide the patient with an instructional handout along with the form. Completed forms would be witnessed and then filed, and the information would be keyed into the structured field in the electronic record either by the clinician or an administrative staff member. The challenges with the existing process were that HCP packets were given to patients inconsistently, and when given, only a small number of patients would complete and return a signed and witnessed copy of their HCP form.

Development of health care proxy interview

We developed the HCP interview based on our prior experience with computer-based medical histories and with advisors from BIDMC’s Conversation Ready project team. (16–18,20,36–40) We used our Converse programming language to write, edit, and administer the interview. (41) We followed the principle that the interview should present text, offer choices, accept responses and reply appropriately with succinctness, cogency and good manners. (41) The program follows a branching algorithm dependent on the user’s response to each question, asking details where needed. It also educates the
user when the user does not know or understand the question being asked. The interview, conducted over PatientSite, is integrated with the patient's electronic health record and extracts and utilizes data from the record where appropriate, such as to show patients any information existing previously in the electronic health record related to their HCP.

**Components of the health care proxy interview**

The HCP interview consists of 4 sections

1. **Education:** This section informs patients of the importance of a HCP and describes the process of appointing one. It also provides a link to a section of detailed educational material, should patients choose to view this. In addition, short educational sequences are presented during the interview based on the user’s responses, such as to inform the patient why it is important to have a signed copy of the proxy form.

   **It would be important to talk to your Health Care Proxy about your wishes (your thoughts, feelings and preferences) as to how you would like to be cared for. It would also be to be sure that your chosen person has agreed to take on this responsibility.**

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**Figure 1** Screenshot from the health care proxy interview, demonstrating the patient education component. All patient data are simulated.
2. Obtaining the Necessary Information: The interview asks each patient to record the information necessary for completion of the proxy form, including the proxy's name, relationship with the patient, telephone number and contact information. It also enables the patient to designate an alternate HCP if so desired.

![Figure 2](image-url)

**Figure 2** Screenshots from the health care proxy interview, demonstrating representative fields. A. Patient's relation with the HCP. B. Name of the HCP. C. Phone number of HCP. D. Address of HCP.

3. Printing the health care proxy form: Patients can print an automatically completed HCP form once they provide the necessary information. The proxy form can also be printed by clinicians in the clinic if they choose to do so. Traditional signatures remain
required in Massachusetts (42), thus we have not as yet enabled an E-signature for the document.

Figure 3 At the conclusion of the interview, an auto-populated health care proxy form may be generated for printing.

4. Submitting the Information: The interview enables patients to save their proxy information and return later to provide additional information when needed, thus reserving their HCP information for review until they are satisfied with its readiness to be shared with their clinicians. The interview then enables the patients, if they so wish, to submit their HCP electronically for review by their clinician and subsequent incorporation into their electronic health record.
Integration with the electronic health record

Patients can securely access both the HCP interview and the results of their interview on their computers through their PatientSite portal. With the interview, patients can choose to provide new HCP information, change existing HCP information, print an automatically completed HCP form, view educational information or stop the interview to be restarted at a later time.

<table>
<thead>
<tr>
<th>Information from your medical record</th>
<th>Information that you provided to this program</th>
<th>Primary Health Care Proxy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: James Doe</td>
<td>Name: Mary Doe</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td>Relationship: Sister</td>
<td></td>
</tr>
<tr>
<td>Telephone #:</td>
<td>Telephone #: 781 555 0497</td>
<td></td>
</tr>
<tr>
<td>Cell phone #:</td>
<td>Cell phone #:</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td>Address: 1 Deaconess Road</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Boston, MA 02215</td>
<td></td>
</tr>
</tbody>
</table>

If there is difference between the information in your medical record and the information you have provided, please enter your latest proxy information, print and sign the health care proxy form and give it to your primary care provider to update the information.

Would you like to

- Add an alternate health care proxy?
- Change your primary health care proxy information?
- Print your health care proxy form?
  (If you have difficulty printing, please ask your clinician’s office staff to print your health care proxy form for you.)
- Learn more about health care proxies?
- Save and stop at this point?

Figure 4 Screenshots from the health care proxy interview displaying previously captured information from the hospital system. A. Display of information in the system. B. Display of patient’s choices.
Once a patient has entered the required information, we ask them if they wish to send it to their clinicians. Once completed, a passive alert to the clinician and staff is generated in the patient’s electronic health record stating the availability of new HCP information through PatientSite. Fig 5 Clinicians can then review this information and use it to update the patient’s electronic health record. Clinicians can also print a copy of the patient’s HCP form, if not yet signed, so it can then be signed by the patient and the two required witnesses.

**Figure 5** Screenshots from the electronic health record, demonstrating the passive alert of the new health care proxy information from PatientSite, and providing information about reconciliation steps. A. Passive alert in patient’s EHR. B. Display of patient entered HCP information with clinician options. C. Information for clinicians informing the source of new HCP information and steps for reconciliation.

**Study Design and participants**
The HCP interview was made available to all PatientSite users. Patients could access the interview through a link on the portal home screen. We informed clinicians of this new application through a broadcast email message, but did not make a similar formal announcement to patients.

Patients were informed at the start of the interview about our plan, with the goal of improving the process, to evaluate their use of the interview and their comments about their experience with the interview. The BIDMC Institutional Review Board approved the study.

**Data Analysis**

We used the Pearson Chi-square statistic with Yates’ continuity correction to compare the difference in the frequency with which HCP information was submitted for review by patients who had at least some HCP information in their electronic health record and by patients who had no HCP information in their electronic health record at the time of the interview. We used the Welch two-sample t-test to compare the age distribution of all PatientSite users with the age distribution of the HCP interview users. We used the R software package, version 3.1.2( [http://www.R-project.org/](http://www.R-project.org/)). We evaluated survey data using methods of qualitative analysis described by Crabtree and Miller.(43) Two authors inductively coded responses and tracked them with Atlas.ti for Mac (Scientific Software GmbH, Berlin). Initially, investigators (BC, AB) reviewed each of the patients’ comments individually, producing a list of key concepts and assigning codes to them. The
investigators then iteratively met to discuss interpretations and compare their codes and then derived themes from the recurrent codes. (43,44)

RESULTS

Of the first 200 patients to complete the interview, the mean age was 55 years (M=55.16, SD=15.16), which was higher than PatientSite users overall (M= 48.1, SD= 15.95), t(199)=6.47, P value=<0.001). Participants were predominantly white (82%); 69.5% of them had a high school degree or higher; their median Charlson Comorbidity Index was 0; and 127(63%) were women.

Table 1: Patient characteristics

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Users</td>
<td>200</td>
</tr>
<tr>
<td>Sex</td>
<td>F=126(63%), M=74</td>
</tr>
<tr>
<td>Age</td>
<td>Median 57 (IQR= 45-68)</td>
</tr>
<tr>
<td>&lt;20 Years</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>20-29 Years</td>
<td>12 (6%)</td>
</tr>
<tr>
<td>30-30 Years</td>
<td>26 (13%)</td>
</tr>
<tr>
<td>40-49 Years</td>
<td>28 (14%)</td>
</tr>
<tr>
<td>50-59 Years</td>
<td>49 (24.5%)</td>
</tr>
<tr>
<td>Age</td>
<td>N</td>
</tr>
<tr>
<td>---------------</td>
<td>-----</td>
</tr>
<tr>
<td>60-69 Years</td>
<td>43</td>
</tr>
<tr>
<td>70+ Years</td>
<td>40</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>164</td>
<td>82%</td>
</tr>
<tr>
<td>Black/African American</td>
<td>12</td>
<td>6%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>4</td>
<td>2%</td>
</tr>
<tr>
<td>Asian</td>
<td>5</td>
<td>2.5%</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>15</td>
<td>7.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest Education</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>5</td>
<td>2.5%</td>
</tr>
<tr>
<td>8th Grade or less</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>1</td>
<td>0.5%</td>
</tr>
<tr>
<td>Graduated from High School/GED</td>
<td>19</td>
<td>9.5%</td>
</tr>
<tr>
<td>Some College/Vocational/Tech program</td>
<td>23</td>
<td>11.5%</td>
</tr>
<tr>
<td>Graduated from College, graduate, post graduate school</td>
<td>97</td>
<td>48.5%</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
<td>7%</td>
</tr>
<tr>
<td>Patient Declined to answer</td>
<td>20</td>
<td>10%</td>
</tr>
<tr>
<td>Patient unavailable to answer</td>
<td>21</td>
<td>10.5%</td>
</tr>
</tbody>
</table>

| Charlson Comorbidity Index | Median=0 (IQR=0-2) |
Ninety-nine (49.5%) of the patients who completed the interview did not have a health care proxy listed in their electronic health record and of these, 78 (78.8%) submitted their HCP information for clinician review. One hundred and one out of the 200 patients who completed the interview had at least some information about their HCP in their electronic health record. Sixty-one of these patients (60.4%) edited their existing HCP information and submitted it for clinician review. Overall, 139 patients submitted their HCP information for their clinician to review and to then update their HCP information in their electronic health record. Status (presence/absence) of HCP information in patient’s electronic health record was significantly associated with submission of HCP information by patients using the HCP interview. Patients who did not have HCP information in their electronic health record were more likely to submit their HCP information using the HCP interview (Chi square statistic is 7.134 with 1 degree of freedom and P value of 0.008).

Table 2

<table>
<thead>
<tr>
<th></th>
<th>HCP information Submitted</th>
<th>HCP information Not submitted</th>
<th>Marginal Column Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCP in OMR</td>
<td>61</td>
<td>40</td>
<td>101</td>
</tr>
<tr>
<td>No HCP in OMR</td>
<td>78</td>
<td>21</td>
<td>99</td>
</tr>
<tr>
<td>Marginal Row Totals</td>
<td>139</td>
<td>61</td>
<td>200</td>
</tr>
</tbody>
</table>

Patients without HCP information in their electronic health record were also more likely to submit this information than were those with any existing HCP information in their
electronic health record (Odds ratio of 2.4 with 95% CI of 1.3-4.6 and P value of 0.005).

Fifty (36%) of the 139 patients who submitted their proxy information, printed a copy of the prefilled health care proxy form to be signed by them and their witnesses. Six patients accessed the educational section of the interview.

Analysis of Patient Comment Data

Seventy-four out of 200 patients who completed the HCP interview (37%) entered comments on their experience. Overall, patients were positive about having the HCP interview available to them through PatientSite and to be able to share their health care proxy information with their clinicians. Upon analysis, the patients’ comments fit into four themes.

First, the interview helped patients become aware of issues surrounding the HCP and to talk about the HCP at home with their families. Patients felt that the interview was easy to use and enlightening; as one user commented "logical, quick and simple process to go through." They liked being able to stop and return later, which allowed them time to discuss the issues with family members and to come to an agreement before appointing their HCP. As two patients put it:

It is very helpful in making sure patients are informed and prepared in this regard.

I think that it is one of the excellent choices for me to have the opportunity to assign my Health Care Proxy or Agent to, at least, one of my eight children to make any
decision that needs to be made in my behalf after having discussed and harmoniously
reached their final judgment.

Second, seeing a link to the HCP interview reminded patients to take the take time to
appoint their HCP, and to submit this information to their clinicians. As three patients
noted:

    I continually forget to bring this up when I visit my primary care doctor so I am grateful
to have this program and get this on file and part of my medical history.

    Useful to have this accessible for patients to complete.

    Very convenient and an easy way to remember to fill the [HCP] form.

Third, the interview created an opportunity to improve the quality of their HCP information
and enabled them to verify their information in their medical record. As one patient stated:

    I believe I have a health care proxy on record but am not sure so this gives me a chance
to make sure.

And fourth, the interview on the computer helped patients tackle the sensitive topic of health
care proxy. One patient commented:

    I think that this is a great way to address a situation that is uncomfortable for many
including me. It will now be addressed. I know when we think of illness & death, we
don’t mention what we should do. This is a great way of handling reality.
Patients also suggested additional features, such as an easier way to print the HCP form, the ability to make edits directly on the HCP form, a provision to add more than one alternate proxy, the ability to enter foreign addresses, and an option to let their clinicians know of their interest in talking with them further about their advance care wishes. Additionally, patients wondered if electronic submission of HCP information might be able to replace the needs for ink signatures:
Of course, one still needs to have witnesses, etc., to finalize the document -- so that remains an impediment, even with the ease of the computer prompts.

DISCUSSION

Our study shows that patients are interested in using our online interview to assign their HCP information, and to share it with their clinicians. Two hundred patients completed the interview in less than 6 weeks from going live, without any formal announcement of its availability. We found that most went on to submit their information for clinician review, and that those without any prior HCP information in their EHR were more likely to proceed and submit their information to the office. This new and corrected information was garnered and added to the EHR by patients alone, and represents a significant way in which patients can help health systems with information entry. Furthermore, our patients’ rate of sharing has been higher than has been reported in studies of computer-based interventions to improve advance directives(7,8,10), potentially because our interview addressed an unmet need for an application that is user friendly, educational and allowing for sharing of HCP information with the EHR. Further more, our findings also show that patients are interested in their clinicians having up to date information about their health care proxy and thus, their care wishes.

Interestingly, of the 200 patients who completed the interview, approximately 30% of
them did not go on and affirmatively submit information for clinician review. One reason may be that these patients did not as yet have all the necessary information. Patients may have also decided to wait to talk with their proxies and their family members before submitting the information for review and incorporation into their medical record. Furthermore, patients who already had HCP information in their electronic record may have considered this to be sufficiently correct or considered their changes to be too minor to be submitted.

The interview users were similar in gender but older than the general population of PatientSite users. The interview users were also predominantly white, healthy, and well educated as well as being more often women. It seems reasonable that older patients would be more likely to think of end of life, and that well educated patients would be more likely to be sufficiently informed to address issues of the HCP. These finding are in line with a previous study that showed older age, female gender, and white race to be associated with higher rates of AD completion. (4) To reach beyond the relatively healthy population, additional outreach efforts will be needed to help the at-risk patient population.

Patients found the interview to be a useful tool when available online. It helped them to be better informed about HCPs and gave them a convenient means to establish or to update their proxy and to discuss issues of the proxy with their family members in the privacy of their homes. Discussion about HCP and advance care planning often takes place in a busy clinic visit or not until a patient has been admitted to the hospital. One could argue that these are not the best settings to discuss matters that require time, deep
thinking, and careful discussion with loved ones. The online interview addresses these needs. It is worthy to note that some patients felt assignment of a health care proxy was important, but found the ‘ink’ signatures on the pre-populated print out from the program to be a barrier to completely closing the loop. They perceived a need for a way to provide their signatures online. This has important legal and policy implication as we strive towards greater patient awareness, engagement and communication of their advance directives.

Our educational section to inform patients of the importance of the HCP and the process of appointing a proxy was accessed by six patients. Patients were offered relevant educational phrases en route through the interview, which we hope sufficed for their purposes. It is likely that some of the participants were already well informed about the HCP and its importance, but had delayed creating one until the availability of our program. While evaluation of this requires further use of our program, we believe that the section will continue to serve a useful purpose.

We developed this interview taking legal aspects as well as clinical workflow into consideration and received endorsements from both our legal and clinical stakeholders. The current process for HCP form submission has a low return rate; and with our interview, the ability to print the HCP form both at the patient’s home and after submission by the patient, at the clinician’s office, increases the likelihood of having an official, signed form available for the patient in case of need.
Our study should be interpreted given its context, conducted as it was in a single health care setting with a home built electronic health record and patient portal. On the other hand, with health care organizations across the United States working towards achieving meaningful use objectives, patient portals are becoming increasingly available, and we believe that our interview would be useful in multiple settings. We had a small sample size and short study period, and our study sample consisted of self-selected patients. Still, a substantial number of these patients had no HCP to start with and were able to establish one by our interview and then enable their clinician to incorporate their new HCP into their electronic record. Moreover, our program continues to be used, with approximately 28 patients taking our interview each week as it remains available to patients of BIDMC who have an active portal account. As with other technology-mediated patient processes, the interview will not replace personal communication with clinicians, but may extend clinicians’ reach for patients who are interested and able to complete the process online.

We are currently conducting a prospective study to evaluate the impact of our interview on the rates of HCP documentation in patients’ electronic health records. We also plan to further explore the reasons why some patients decide not to submit their HCP information for incorporation into their electronic records and why so few patients availed themselves of the educational section. This should help us improve our interview.

CONCLUSION
Though substantial work has been done to educate and help patients in advance care planning, gaps remain in closing the communication loop. Our study shows that our HCP interview can be an effective means to help patients to assign and communicate their HCP information. We believe our approach can help to enhance communication between patients and clinicians and be an important assistant to patients as they plan for the future.

Acknowledgements

The authors would like to thank the Larry Markson, M.D., Julie Rockwell and the BIDMC Information Systems team, Lauge Sokol-Hessner, M.D, Jennifer Greene and the Conversation Ready team at BIDMC, David Sontag, J.D, Roger Davis, ScD, Margaret Jeddry, Melek Somai, M.D. and Christina Cain for their help during this study.

Contributors

AB, BC, HK, CS and WS designed and developed the interview. AB, BC and HK conducted the analysis. All authors contributed to drafting or edited the manuscript.

FUNDING

This work was funded by National Library of Medicine grant T15LM007092 and Agency for Healthcare Research and Quality grant R01HS021495.
COMPETING INTERESTS

WS is on the medical advisory board of Qur, a health IT start up developing a self-driving diagnostic program. CS serves as a consultant for Cerner and Allscripts, a member of the physician advisory board of Elsevier, a council member of Health on the Net foundation and a shareholder and director at Intelligent Medical Objects.

Ethics approval

Beth Israel Deaconess Medical Center Institutional Review Board

Provenance and peer review

No commissioned; externally peer reviewed

References


42. General Laws: CHAPTER 201D, Section 2 [Internet]. [cited 2015 Feb 20]. Available from: https://malegislature.gov/Laws/GeneralLaws/PartII/TitleII/Chapter201D/Section2

Additional figures

Figure 6 Figure showing age distribution of PatientSite user population
Figure 7 Figure showing age distribution of HCP interview user population