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Feasibility of Providing Web-based Information to Breast Cancer Patients Prior to a Surgical Consult

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Abstract

Objective—Patients facing decisions for breast cancer surgery commonly search the internet. Directing patients to high quality websites prior to the surgeon consultation may be one way of supporting patients' informational needs. The objective was to test an approach for delivering web-based information to breast cancer patients.

Methods—The implementation strategy was developed using the Replicating Effective Programs framework. Pilot testing measured the proportion that accepted the web-based information. A pre-consultation survey assessed whether the information was reviewed and the acceptability to stakeholders. Reasons for declining guided refinement to the implementation package.

Results—82% (309/377) accepted the web-based information. Of the 309 that accepted, 244 completed the pre-consultation survey. Participants were a median 59 years, white (98%), and highly educated (>50% with a college degree). Most patients who completed the questionnaire reported reviewing the website (85%), and nearly all found it helpful. Surgeons thought implementation increased visit efficiency (5/6) and would result in patients making more informed decisions (6/6).

The most common reasons patients declined information was limited internet comfort or access (n=36), emotional distress (n=14), and preference to receive information directly from the surgeon (n=7).

Conclusion—Routine delivery of web-based information to breast cancer patients prior to the surgeon consultation is feasible. High stakeholder acceptability combined with the low

implementation burden means that these findings have immediate relevance for improving care quality.

Keywords

implementation; decision support; breast cancer surgery; web-based information; internet

1. INTRODUCTION

The internet is a readily accessible and frequently utilized resource for patients seeking health information about a new diagnosis and treatment options [1]. Cancer patients in particular have high internet utilization, with some studies reporting more than 90% of patients going online to learn about their disease [2–4]. However, while the use of online information to aid in patient education is promising, challenges related to patient access to and comfort with the internet may limit use and lead to disparities in care. Even for those patients with reliable internet access, variability in their internet skills may represent barriers to effectively using this resource [5]. Previous studies have demonstrated that patients using search engines to find information often end up with huge numbers of results that many times are of poor quality. Sorting through these results to identify sites with complete and accurate information from trustworthy sources requires sufficient health and eHealth literacy [6–9]. Having health care practitioners direct patients to online sites known to be of high quality may be one solution to address this challenge and support diverse patients' needs and desire for information about their cancer.

To test this hypothesis, we focused on women newly diagnosed with breast cancer. Almost 250,000 women are diagnosed annually with local-regional breast cancer and face the decision for surgical management of their breast cancer [10]. Successful surgical planning is dependent upon patients being both well informed and engaged in the decision making process [11–13]. During the “informational gap” between diagnosis and when they meet their surgeon, breast cancer patients often turn to the internet for information and guidance [4,14,15]. However, our prior work demonstrated that the information they find to support their decision for breast cancer surgery is frequently of poor quality [6]. We hypothesized that having the breast clinic deliver high quality web-based information directly to breast cancer patients prior to the surgical consultation would be a valuable way to increase their knowledge about their treatment options and better prepare them to actively participate in decision making.

Although many clinics may currently share web-based information with their patients, this most commonly occurs after the surgical consultation. Routine delivery of web-based information *prior* to the surgical consultation is more challenging, requiring changes to standard clinical flow. Embedding the delivery of web-based information into routine clinical flow in a manner that is sustainable and acceptable to stakeholders requires careful consideration of factors unique to each clinic, and development of an implementation process that is sensitive to those factors [16,17]. No description of the implementation strategies necessary to embed the delivery of web-based information into routine clinical flow currently exist. Therefore, the objectives of this study were to develop an

implementation strategy for delivering web-based information to breast cancer patients prior to the surgical consultation and to examine the feasibility of this approach within an academic and a community breast program.

2. METHODS

2.1 Implementation strategy development

Development of the implementation strategy was guided by the Replicating Effective Programs framework (Figure 1) [18]. We elicited feedback from stakeholders, including patients, nurses, and surgeons, on how to “seamlessly” incorporate pre-consultation delivery of web-based breast cancer information into routine care, and identify anticipated implementation barriers. Based on this feedback, we identified core elements critical to successful implementation: 1) Identification of a surgeon champion and change team to guide activities for eliciting “buy-in”; 2) Delivery prior to the surgical consultation when patients’ informational needs are highest in order to prepare patients to play an active role in decision making [14,15]; 3) Direct delivery to patients; and 4) Performance of audit-feedback early in implementation to maximize the proportion of patients reached. In the developed implementation strategy, patients were offered the web-based information by nursing staff or a breast cancer navigator by telephone either at the time of diagnosis or when their appointment in the surgery clinic was made; this conversation followed a script that addressed anticipated barriers to patients accepting the information. Patient were then emailed links to web-based information containing content about their diagnosis and treatment options to review prior to the initial meeting with their surgeon. During our study period, patients were sent one of two forms of web-based information: 1) websites rates as high quality [6] that were developed and supported by nonprofit organizations (Breastcancer.org; American Cancer Society-www.cancer.org/cancer/breastcancer/index; National Cancer Institute-www.cancer.gov/cancertopics/types/breast), or 2) a commercially developed decision aid developed through a cooperative agreement by Health Dialog and the Informed Medical Decisions Foundation.

2.2 Feasibility testing of implementation strategy

Patients were eligible for participation in the feasibility study if they were newly diagnosed with stage 0–3 breast cancer, were 18 years of age or older, and were considering breast surgery at the University of Wisconsin. We excluded patients who were coming to our center for a second opinion or patients with recurrent cancer. Additional study specific exclusion criteria included the inability to read or comprehend health information in English (as the web-based materials were only available in English) or patients lacking decision-making capacity (e.g. dementia). Finally, patients were required to have an email address that the web-based information could be sent to.

Newly diagnosed breast cancer patients were screened for study eligibility by the breast center nurses (4/2014–6/2016). Eligible patients were then offered the study by the nursing staff or breast cancer navigator either at the time of diagnosis or when their appointment in the surgery clinic was made, and oral consent was obtained. For patients who declined, reasons for declining and patient age were recorded without other identifying information.

Participants were administered a questionnaire prior to their first surgical consultation to assess time spent reviewing web-based information (no review, <15 minutes, 15–60 minutes, >60 minutes), overall helpfulness of the links (scale from 1–10), education history (high school or less, some college, college degree, graduate school degree or higher), and baseline internet use (multiple times a day, about once a day, a couple times a day, less than once a week). For patients who completed the questionnaire, a chart review was performed and information pertaining to tumor characteristics, clinical and pathologic disease staging, and surgical treatments received was abstracted. We collected zip code+4 for each participant and linked this to the Area Deprivation Index to generate an estimate for socioeconomic status; patients were grouped into quartiles using the national cut-points [19,20]. No additional data were collected for patients who did not complete the questionnaire. As this study is focused on factors related to the feasibility, we will report survey data on the time spent reviewing and patient perceived helpfulness of the emailed websites.

After completing patient enrollment, breast surgeons were emailed a brief, anonymous survey to assess their perspectives on the impact of the web-based information on patient interactions. The survey was adapted from the Ottawa Practitioner Opinion Survey and included questions on the perceived impact of the web-based information on efficiency of the clinic visit, patient satisfaction with clinic visit, ability of information to support informed patient decision making, and overall benefit versus harm to patients [21]. The study protocol was approved by the UW Human Subjects Committee and all participants gave informed consent.

2.3 Analysis

We calculated the proportion of patients that accepted the web-based materials when offered. Descriptive statistics were generated for those patients who accepted study participation and who completed the questionnaire. We summarized the time spent reviewing the websites, reasons for non-review, and patients' perceptions on helpfulness of the websites. We used univariate statistics to examine the association between patient characteristics, perceived helpfulness of the website and likelihood to review websites. We summarized reasons why patients declined participation and compared age between participants and nonparticipants (t-test). Simple summary statistics were generated from the clinic stakeholder survey data.

3. RESULTS

Overall, 377 patients were found to be eligible and offered the web-based material using the implementation process outlined (Figure 2). Three hundred and nine patients accepted the material, for a final acceptance rate of 82%. 65 patients accepted but did not complete the questionnaire, leaving 244 participants. Sociodemographic details for participants are listed in Table 1. Consistent with our breast center demographics, the majority of patients were white, educated, and had a high baseline internet use. There were no differences in the characteristics of the patients seen at the academic compared with community breast surgery clinic.

Of the 244 participants, 85% (208/244) reported reviewing the web-based material prior to their surgeon visit. Thirty-eight percent of participants who reviewed the web-based material

spent more than an hour, 54% 15–60 minutes, and 9% spent less than 15 minutes. The vast majority of patients (80%) found it to be helpful. No patient factors (age, race, education level, socioeconomic status, baseline internet use) were associated with perceived helpfulness of the web-based material.

Patients who reviewed the material reported a higher baseline internet use than those who did not review, with 73% using the internet multiple times a day amongst those that reviewed compared with 55% using the internet multiple times a day among those not reviewing the material ($p=0.004$). No differences in age, race, education level or socioeconomic status was observed. Patients who did not review the decision aid prior to the consult ($n=36$) cited a variety of reasons, most commonly not receiving the study email with the website links ($n=12$) and not having enough time ($n=10$). Other cited reasons include not being “ready”, feeling it was unnecessary, and computer/internet issues.

Of the 68 patients that declined participation, the most common reason cited was limited access or comfort with the internet (53%, $n=36$). Non-participants were older than participants (median age 66 [range 37–92] vs. 59 [range 27–80], $p=0.0001$), with those declining due to lack of internet access representing an even older patient cohort (median 72 years, range 50–92). Other cited reasons for declining included emotional distress around the diagnosis ($n=14$), preferences to receive cancer information directly from their surgeon ($n=7$), and a general lack of interest in reviewing any internet information ($n=2$). Nine patients did not provide a reason.

All six participating surgeons ($n=3$ academic and $n=3$ community) completed the survey assessing their perspectives on the impact of the web-based material on patient interactions. Most surgeons were able to tell which of their patients had reviewed the web-based materials ($n=4$). All of the surgeons thought that routine use of the web-based material prior to the visit was a “reliable method of helping patients make decisions” and would result in “patients making more informed decisions”. Further 5/6 surgeons thought that use of this material would increase patients’ satisfaction with their surgical visit. Implementation of the web-based material was viewed positively. Most surgeons (5/6) felt that implementation did not involve any major change to how they usually did things and that use of the web-based material made the clinic visit more efficient.

4. DISCUSSION AND CONCLUSION

4.1 Discussion

In this study, we demonstrated the feasibility of delivering web-based information to patients prior to their surgical consultation. This approach addresses an important clinical gap by providing patients with high quality information at the time when they most benefit from it, i.e. in the information gap between diagnosis and the first surgical consult. By selecting high quality websites and providing them directly to patients, this approach ensures patients receive high quality information without requiring them to have the eHealth literacy to conduct their own internet searches and sift through the identified information. Importantly, we found that most women were interested in receiving the information, reviewed the material when it was sent, and found it to be highly beneficial.

We did experience some barriers to this approach, some of which can be addressed through modifications of our approach to delivering the web-based information. For women who were interested in receiving the web-based material, the most common reason for non-review was not receiving the material, such as would happen if the email with the website links went to a SPAM folder rather than to the patient's inbox. Highlighting the window in time in which patients could expect to receive the material and reminding them to check their SPAM folder are important steps to ensuring patients who want the information receive it, thereby minimizing patient frustration. Patients also reported having "no time" to review the material prior to the surgeon visit. In current practice, timely receipt of care after a breast cancer diagnosis, including a timely referral to see a surgeon, is a frequently tracked quality metric. This in itself is likely beneficial to patients as it decreases the "informational gap" between diagnosis and surgeon visit, but it does limit the technical ability to deliver information to patients for review prior to the surgeon visit. In our experience, these patients often still referred to the web-based material and used it as a supplemental resource after their initial surgeon consultation.

For patients who declined the study entirely, the most common reason observed was a reported lack of access or comfort with the internet. Potential mechanisms for increasing reach for this type of web-based intervention would be to assist patients in identifying alternative options for reviewing the web-based material, including emailing the material directly to family members to review with patients and providing iPad access to the websites in the clinic. Other frequently cited reasons for declining included emotional distress and a preference to receive information directly from the surgeon. Both of these potentially may be addressable by describing to patients how reviewing the web-based material may help them cope with the stress of their diagnosis and including a strong surgeon endorsement of the web-based material as a supplement – and not a replacement – to the consultation with their surgeon.

Our study does have some limitations. First, because we were assessing feasibility of web-based material delivery in the context of a research study, we could not determine whether patients declined to receive the web-based material because of the material itself or because of the additional requirements of study participation (i.e. oral consent, study questionnaire, etc.). If patients' response of being "too overwhelmed" related to study participation, our results would underestimate the proportion of women interested in receiving web-based material. Additionally, as a result of our study design, we have limited information about patients who declined the web-based material (only reason for declining and age was recorded). Further, we did not systematically capture patients who did not meet eligibility criteria for our study (i.e. non-English speaking, no email address). This limits our ability to fully understand how these patients may differ from those who accepted. In our study, we intentionally limited the surgeons' evaluations to minimize the burden; this does represent another limitation. Further, eligibility criteria were associated with our study (excluded second opinions, recurrent cancer, etc.) and not every patient seen in our breast center was offered the web-based material, limiting our ability to generate a clinic-level estimate of reach. The implementation strategy we employed in this study involves nursing staff or a breast center navigator introducing the web-based information. This may not reflect usual

clinic practice in some settings. We believe that this information could also be introduced by the clinic schedulers, broadening feasibility of this approach.

One final limitation relates to the patient population in our study. Although we have shown our approach to delivering web-based material to be successful at an academic and a community clinic, patients participating in this feasibility study were predominantly educated, affluent, and white. Some concern exists that a web-based approach may selectively exclude certain at-risk patient populations, such as older patients, those with lower education, and those with lower income. Importantly, internet use has increased steadily over the past decade, with the greatest gains in these at-risk patient groups (Figure 3) [22,23]. Further study of our approach is needed in clinics that provide care to more diverse patient populations to confirm feasibility and ensure our approach will mitigate, rather than worsen, existing disparities.

4.2 Conclusion

In conclusion, we demonstrated the feasibility and acceptability of delivering web-based material to breast cancer patients prior to the surgical consult. Although many clinics may currently share web-based information with their patients, this is the first description of the implementation strategies necessary to embed the delivery of web-based information into routine clinical flow. Ongoing research will assess the impact of receiving web-based information prior to the surgical consultation on patient knowledge.

4.3 Practice Implications

The implementation strategies we employed can be used with any web-based information that a clinic feels is most appropriate for their patient population and is applicable across diseases. For clinics with lower resources, sending patients links to websites developed and supported by non-profit organizations (as opposed to commercially available decision support systems) may be a reasonable option. In our study, patients reviewed the information as highly beneficial regardless of the source suggesting that the timing of information delivery mattered more than the specific information shared. In addition, we also identified opportunities to address the barriers to delivering this information, which should increase the reach of this type of intervention. Given the low burden associated with implementing this intervention and strong positive reviews by both patient and surgeon stakeholders, these findings have immediate relevance for improving care quality.

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Fig 1.
Replicating Effective Programs framework used to develop the implementation strategy

Fig 2.
Acceptance and review of web-based material in an academic and community breast surgery clinic

Fig 3. Trends in use of internet for American Adults. Adapted from the Pew Research Center surveys, 2000–2015

Table 1

Characteristics of patients who accepted the web-based material *

	N (%)
Age (median, range)	59(27–80) years
Race	
White/Non-Hispanic	239 (98%)
Non-white/Hispanic	5 (2%)
Years of education	
High school or less	23 (9%)
Some college (no degree)	60 (25%)
College degree	89 (36%)
Graduate degree or higher	63 (26%)
No response	9 (4%)
Area Deprivation Index (based on national data)	
Quartile 1 (lowest SES)	7 (3%)
Quartile 2	18 (7%)
Quartile 3	62 (25%)
Quartile 4 (highest SES)	129 (53%)
Missing	28 (12%)
Internet experience	
Less than once a week	6 (3%)
A couple of times a week	17 (7%)
About once a day	39 (16%)
Multiple times a day	172 (70%)
No response	10 (4%)
Stage	
Stage 0	35 (14%)
Stage 1	124 (51%)
Stage 2	74 (30%)
Stage 3	11 (5%)

* sample limited to those that completed the questionnaire