ABSTRACT
To assess our collective understanding of how consumers use patient portals, we conducted a systematic literature review focusing on understanding patients and caregivers’ perceptions, needs, requirements, and use of patient portals with the goal of informing the design of effective patient portals. Through multiple rounds of screening, we identified 56 relevant publications for analysis. The preliminary analysis suggested that patient portals are implemented in a wide range of health care settings, ranging from large medical centers to small primary care facilities. Patient portals primarily target patients with chronic conditions. Many aspects of the use of patient portals were covered in the literature, including users’ use of specific portal functions (such as managing medications and accessing imaging results), their attitudes toward patient portals, and barriers to patient portal use. Our findings call for more attention from information science researchers to contribute to this important area.

Keywords
User studies, patient portals, systematic review

INTRODUCTION
Patient portals are web-based portals that enable patients to access their personal health information, communicate with providers, and use various self-management tools (Otte-Trojel, de Bont, van de Klundert, & Rundall, 2014). In most cases, patient portals are tethered to health care institutions’ existing electronic health record (EHR) systems. That is, the data in a patient portal are owned and managed by the health care organizations. The recent years saw a rapid adoption of patient portals among health care organizations, suggesting that they may soon become a standard part of care (Sarkar & Bates, 2014). At the same time, preliminary evidence about positive impacts of patient portals on health outcomes has started to emerge, particularly for patients with chronic conditions. For example, a survey of 1871 US veterans infected with HIV found that the use of the VA patient portals was associated with 90% or greater adherence to antiretroviral therapy (McInnes et al., 2013).

However, whether or not patient portals are effective in empowering patients and improving quality of care remains largely inconclusive (Kruse, Argueta, Lopez, & Nair, 2015). A major challenge is that the adoption rate of patient portals is still low. In most studies, the adoption rate was less than 50%. Some were even lower (Yamin et al., 2011). Many reasons contribute to this low adoption rate, including users’ demographic and socioeconomic status (e.g., old age, low education and income, and low health literacy), system usability, and a lack of awareness among patients (Lyles, López, Pasick, & Sarkar, 2013; Ronda, Dijkhorst-Oei, & Rutten, 2014).

METHODS
To achieve a comprehensive understanding of how patients use patient portals, we performed a systematic literature review of user studies of patient portals. A systematic review is a literature review that focuses on identifying and appraising research evidence about a topic in an exhaustive manner, and summarizing what is known about the topic (Crowther, Lim, & Crowther, 2010). Our systematic review followed the following steps:

Step 1: Database search
Databases were selected from the electronic journal databases available through the authors’ institution. Given the focus of this literature review, databases were selected from the following eight fields: Communication, Communication Sciences and Disorders, Communication Studies, Consumer Health, Library and Information
Science, Medicine, Nursing, and Psychology. To be included, a database must:

1. Contain journals that publish peer-reviewed articles. Databases that only contain dissertations, e-books, book reviews, video/audio, encyclopedias, images, factual data, regulations/laws, citations, or directories were excluded.
2. Allow keyword search in the title or abstract.
3. Be relevant to the scope of the present review.
4. Contain articles with full text written in English.

Based on these criteria, nine databases were selected (the year coverage of each database listed below was the coverage available through the library of the authors' institution). These included:

1. ACM Digital Library (1985 - present);
2. PubMed/Medline (1950 - present);
3. Communication & Mass Media Complete (CMMC, 1920 - present);
4. Cumulative Index to Nursing & Allied Health (CINAHL) Plus with Full Text (1937 - present);
5. PsycINFO (1887 - present);
6. Sociological Abstracts (1952 - present);
7. Cochrane Library (Dates of coverage vary);
8. Health Source: Nursing/Academic Edition (Dates of coverage vary);

Additionally, to ensure a broad coverage, we also searched Google Scholar, resulting in a total of ten databases.

Step 2: Keyword search

In June 2015, using the search term “patient portal*,” one of the authors performed keyword searches in the Title and Abstract of the nine databases selected from the library’s resources and searches in Title in Google Scholar. The following inclusion/exclusion criteria were used for this round of the searches:

1. Only included papers from peer-reviewed journals or conference proceedings.
2. Only included papers with full text written in English.

After removing duplicates, a total of 253 unique records were identified. The title and abstract of these articles were downloaded to a reference management tool, Zotero, for further screening.

Step 3: Title/abstract screening – first round

The following inclusion/exclusion criteria were used for this round of screening:

- Included publications reporting original research findings.
- Excluded non-empirical publications (e.g., abstracts, editorials, commentaries, book reviews, viewpoints, opinions).

One coder used this criterion to code the articles, and a total of 72 articles were excluded, leaving 181 articles for further analysis.

Step 4: Title/abstract screening – second round

The remaining 181 articles were examined by two independent coders (two of the authors) using the following criteria:

1. To be included, papers must focus on empirical results from user studies of patient portals, involving patients as end users, that is, reporting patients’ use of patient portals. This included both studies of patients’ actual use of patient portals and studies of user perceptions, needs and requirements;
2. Only included papers with full-text, not just abstract.
3. Papers that only reported background information about patient portals such as the adoption rate of patient portals or the characteristics of adopters were excluded.
4. Papers that only analyzed messages in patient portals were excluded;
5. Papers that only analyzed the use of patient portals by clinicians or clinicians’ attitudes and preferences towards patient portals were excluded.

Three of the authors discussed these criteria and used them to independently code the first 20 records. After further discussion, we reached a consensus. The inclusion/exclusion criteria and notes about the coding decisions and rationale for the first 20 records formed the material to train a graduate research assistant (GRA) to screen the rest of the records. The GRA, following the examples of records 1-20, practiced coding records 21-40. Meanwhile, one of the authors also independently coded these same 20 records, and we compared the coding results from these two independent coders. The comparison shows that the raw agreement between these two independent coders was 85% (17/20 in agreement). However, to factor in the chance that the two results might agree randomly, especially in a case where there is a binary classification, we used Cohen’s (1960) Kappa, a standard measure of inter-rater reliability. The resulting Kappa was 0.5. Based on Landis and Koch’s (1977) benchmarks, this represents moderate agreement, which is an encouraging preliminary result.

All authors then discussed the three items that the two coders disagreed on, consulted the full text of these items, and then reached a consensus (which included tweaking the criteria for clarity and consistency). The two coders then
coded the remaining records. In total, 125 records were excluded, leaving 56 records in the final dataset.

Step 5: Data extraction
For the preliminary analysis, one of the authors reviewed the citation records of the 56 included articles and coded the following information concerning each article in Excel: year of publication, journal where the article was published, participants involved, aspects of use of patient portals studied, and research methods. (In further analysis in the future, we will identify the characteristics of the use of patient portals, including usage patterns, barriers and facilitators to the use, and users’ expectations.)

RESULTS
The 56 articles in the final sample were published between 2005 and 2015. The number of publications between 2005 and 2011 was stable, ranging from one to four each year. 2012 saw an increase of attention to this topic, with 9 (16.1%) articles being published. The peak appeared in 2014, with 16 (28.6%) articles being published in this year. The level of attention to this topic continues to develop. The year 2015 so far (early June when our searches were performed) has already yielded eight articles.

The 56 articles were published in 34 unique journals and conference proceedings. Journals that published the most number of articles were the Journal of Medical Internet Research (10 articles) and Journal of American Medical Informatics Association (9 articles). The most common conference venue was the American Medical Informatics Association Annual Symposium (3 articles).

The purpose of this systematic review was to examine patients’ use of patient portals to inform the design of effective patient portals. The included articles examined a number of different aspects of patients’ use of patient portals. These include patients’ use of specific functions of patient portals (e.g., accessing radiological reports, managing medications, and using electronic messaging to communicate with health care providers), patterns of usage, patients’ perceptions of and attitudes towards patient portals, barriers to using patient portals, and disparities in the use of patient portals among underserved user groups (e.g., older adults, patients with low education levels, and patients with low English proficiency and literacy levels).

In the included articles, the participants were predominately patients associated with specific hospitals or clinics. Only one article reported studying general health consumers, and four articles included parents or primary caregivers. Most patient portals target patients with chronic conditions, led by diabetes, with 12 articles reporting studies related to patients living with diabetes. Other commonly studied chronic conditions included HIV/AIDS (1 article), lung cancer (1), multiple sclerosis (1), and asthma (1).

A number of research methods were used to study patients’ use of patient portals. The most popular methods were survey (19 articles), transaction log analysis (12 articles), randomized controlled trial (8 articles), observation of users using specific systems (8 articles), focus group (7 articles), various forms of interview (including in-depth, semi-structured, and structured telephone interviews, 5 articles), and review of patients’ medical records (3 articles). In about a dozen articles, several different methods were used. The most common pairing of methods was between transaction log analysis and either the review of patients’ EHRs or survey, particularly when the purpose of the article was to examine the relationship between patients’ characteristics or the use of portals and health outcomes.

DISCUSSION
Patient portals, a new health information technology with the promise to improve patients’ access to their clinical data, have received great attention from policy makers, health care organizations, and patients themselves. However, the adoption rate is still low. This systematic review intends to review the current research evidence concerning patients’ use of patient portals to shed light on the design of effective patient portals to encourage user adoption and use. The preliminary analysis uncovered a number of aspects from which the use of patient portals has been studied in the literature. As this preliminary analysis is a part of a larger study, in further analysis in the future, we will identify specific usage patterns, barriers and facilitators to the use of patient portals, as well as users’ expectations.

The preliminary results also indicate that most of the selected studies were conducted in clinical settings and published in health-focused journals. Only one article was published in an information science journal, Journal of the Association for Information Science and Technology. This finding invites information science researchers to contribute more actively to the study of patients’ use of patient portals from a human information behavior perspective.

ACKNOWLEDGMENTS
This research was funded by the Center for Identity at The University of Texas at Austin.

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