Finding Orthopedic Patients Lost to Follow-up for Long-term Outcomes Research Using the Internet: An Update for 2012

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Abstract: The Internet is available to researchers as a tool for studying long-term outcomes, but no recent research exists on how to best use it. The authors hypothesize that using the Internet can be at least 75% effective in locating patients lost to follow-up. With Institutional Review Board approval, the authors searched for 66 patients lost to follow-up after a period of 10 years or more with no contact. They tested an Internet searching protocol developed in 2004 and developed an alternate protocol. In all, 74% (49/66) of patients were located.

Locating patients who have become lost to follow-up can be problematic for long-term outcomes studies. Conducting searches for patients’ whereabouts through traditional means, such as driver’s license records and telephone books, can be highly expensive and time-consuming.\(^1,2\)

With the proliferation of data online, many researchers have begun to use the Internet to find patients, with varying levels of success. For example, in 2004, King et al\(^3\) developed a protocol that used only free Web sites (Figure 1) and achieved a 95% success rate in finding patients. However, 2 years later, Lovell and Morcuende\(^4\) tested this protocol and found it to be only 21% effective.

Many variables affect success rates, including patient population: King et al\(^3\) studied patients who underwent total knee arthroplasties and Lovell and Morcuende\(^4\) studied patients with childhood clubfoot. Some studies have suggested that factors such as sex or childhood socioeconomic status may strongly influence the ability of researchers to locate patients for long-term follow-up.\(^5\) Others have argued that poor outcome influences patients’ desire to participate, biasing study results.\(^2\) However, lack of data predicting the difficulty of finding certain patient cohorts makes studying its effectiveness difficult.

The current authors conducted an Internet search on a cohort of patients lost to follow-up in an attempt to re-evaluate the current effectiveness of the protocol detailed by King et al\(^3\) and hypothesized that the protocol would be able to locate at least 50% of their patients. They also attempted to create an alternate, contemporary protocol for searching for patients based on modern Web sites and resources. They hypothesized that the new protocol would be at least 75% effective.

Materials and Methods

Institutional Review Board approval was obtained. Using Current Procedural Terminology billing codes, a consecutive series was identified of 211 patients who underwent mini-open carpal tunnel release performed by a single surgeon between 1996 and 2000. All interventions occurred a minimum of 10 years prior to the initiation of the study. Cases were excluded if significant procedures were performed in addition to carpal tunnel release. The authors attempted to locate all 211 patients using medical record information but were unsuccessful with 66 patients, who were classified as being lost to follow-up.

Therefore, the current study group comprised 66 patients (48 women and 18 men). Age range at surgery was 27 to 92 years. Fifty-seven patients were listed in the medical records as possessing an address in Massachusetts. Average
time interval since patients were last seen at the authors’ institution for any reason was 8 years. The following data were extracted from the medical record: name, name of next of kin or other contact person, birthday, last known address, and last known telephone number.

The search was conducted in 2 stages. The authors tested the efficacy of the King et al scheme in the first stage and attempted to develop an alternate method of locating patients in the second stage. Other research studies have used personal contacts to augment searches, but the authors were not able to do so due to Institutional Review Board restrictions. The search was conducted entirely on the Internet using a mixture of free and paid Web sites. Once patients were located, they were asked to complete the Levine-Katz Carpal Tunnel Questionnaire, a validated instrument for the assessment of carpal tunnel syndrome.

King et al protocol

In the first stage, the protocol from King et al was followed as delineated (Figure 1). After 7 years, many of the resources used by King et al had changed significantly. For instance, the Social Security Death Index was no longer freely available on ancestry.com, as reported by King et al. Rather, access was obtained via legacy.com, as well as through the Research Patient Data Repository, a resource at the authors’ institution. In addition, superspages.com, switchboard.com, and anywho.com appeared to rely on the same database of information because they produced identical results. Whowhere.com explicitly credits its searching service as provided by whitepages.com. When consolidating sources, redundant Web sites were removed, and only anywho.com, people.yahoo.com, and whitepages.com were retained for the current study.

New Protocol

In the second stage, alternate search methods were used to locate patients lost to follow-up (Figure 2). Lovell and Morcuende used driver’s license records, reunietonight.com, and intelius.com to achieve a 54% success rate. The current authors used peoplefinders.com, a competitor of intelius.com, because Lovell and Morcuende did not have particularly strong results. They also added spokeo.com, a self-proclaimed deepnet search engine, and zabasearch.com, a free public records search engine. Both peoplefinders.com and spokeo.com charged a small fee.

RESULTS

Using the protocol of King et al, led to a success rate of 58% (38/66), but using the new search protocol led to a success rate of 74% (49/66), increasing the overall contact rate from 69% (146/211) to 92% (194/211). The Social Security Death Index was highly effective, locating 93% (25/27) of deceased patients. The remaining 2 patients were determined to have died only after contacting their homes. Anywho.com and people.yahoo.com were ineffective, yielding 8 and 9 patients, respectively, of the 41 presumed living. Whitepages.com was more effective, finding 12 patients. Of the sites included in their alternate search protocol, zabasearch.com and spokeo.com were both ineffective. Zabasearch.com was outdated and only yielded 11 correct results. Spokeo.com was moderately better, with 15 patients found. In contrast, peoplefinders.com was highly useful, with 20 patients found. In addition, using their alternate protocol augmented the use of whitepages.com, increasing its yield to 20 total patients (Figure 3). In total, the authors located 27 deceased patients and 22 living patients.
Of the 66 patients lost to follow-up, 27 were deceased, 22 were alive, and 17 could not be located. Eighteen of the 22 patients who were found participated in the research. These patients are referred to as the hard-to-find group. For comparative purposes, the patients who were not lost to follow-up and responded to the questionnaire (n=94) are referred to as the easy-to-find group.

The groups differed in several ways. On average, the hard-to-find patients were 6.5 years younger, were more likely to be women (83% vs 68%, respectively), and reported fewer comorbidities (33.3% reported 3 or more vs 56.5%, respectively) than the easy-to-find patients. Bivariate analysis revealed that the hard-to-find patients had better function. The hard-to-find patients were statistically associated (P=.04) with superior Levine-Katz function scores of 2 or less (scale of 1 to 5, with 5 being the worst).

The direct costs of using the Internet were low. Payments to access peoplefinders.com and spokeo.com cost a total of $15.90 ($0.95 for peoplefinders.com and $14.95 for spokeo.com). Additional untalled costs include computer equipment, an Internet connection, electrical power, and salary for research staff. Although computer and Internet use is nearly ubiquitous in the modern day, these costs—especially personnel—remain important considerations.

**Discussion**

Recent studies using the Internet to locate patients lost to follow-up report widely varying levels of success (Table 1). Aside from the previously reported range of 21% to 95%, a study by Ward et al achieved a 90.6% success rate with patients who underwent Charcot-Marie-Tooth surgery. The period of no contact was 26.1 years. Although Lovell and Morcuende had a 50-year period of no contact, the Ward et al study indicated that a long interval of no contact may not be a barrier to achieving a high success rate.

An additional variable is the type of procedure performed. Total knee arthroplasty and Charcot-Marie-Tooth surgery are extensive procedures in which the patient is expected to follow-up for numerous years. In contrast, the standard of care for carpal tunnel release procedures is limited, and follow-up rarely lasts more than 1 year. It is beyond the scope of this study to determine what the effect of short-term follow-up is, but further research is needed on this topic.

It has been suggested that the difficulty in finding patients is related to outcome, with patients experiencing poorer outcomes being less willing to participate in research. This association was not found to be the case in the current study because a statistically significant relationship was found between hard-to-find patients and good Levine-Katz function scores (defined as greater than 2) compared with easy-to-find patients. This may be related to the age difference between the 2 groups: the hard-to-find patients were younger than the easy-to-find patients. Another potential confounding factor is the disparate sizes of the 2 cohorts: 18 hard-to-find patients and 94 easy-to-find patients.

The authors were able to successfully find more than 50% of patients using the King et al protocol, but their rate of 74% (49/66) with the new protocol falls just short of their hypothesized value of 75%. A sizeable portion of patients lost to follow-up were elderly and had died. This contributed to the success rate because it was easy to locate these patients using the Social Security Death Index. The new protocol also appeared to successfully locate patients who had moved away. Twelve of the 22 living patients located had moved to a different state. The search took an estimated 100 hours.

<table>
<thead>
<tr>
<th>Study</th>
<th>Surgery</th>
<th>Time Since Surgery, y</th>
<th>Free Sites, % (n/N)</th>
<th>Free and Paid Sites, % (n/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>King et al</td>
<td>Total knee arthroplasty</td>
<td>5</td>
<td>95 (37/39)</td>
<td>–</td>
</tr>
<tr>
<td>Lovell and Morcuende</td>
<td>Clubfoot</td>
<td>50</td>
<td>21 (26/126)</td>
<td>54 (68/126)</td>
</tr>
<tr>
<td>Ward et al</td>
<td>Charcot-Marie-Tooth</td>
<td>26.1</td>
<td>–</td>
<td>90.6 (35/39)</td>
</tr>
<tr>
<td>Current study</td>
<td>Carpal tunnel release</td>
<td>12</td>
<td>57.5 (38/66)</td>
<td>74 (49/66)</td>
</tr>
</tbody>
</table>

**Figure 3:** Results of Web sites used to search for patients lost to follow-up.

**Table 1:** Studies Using the Internet to Locate Orthopedic Patients for Long-term Outcomes Follow-up

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**Figure 3:** Results of Web sites used to search for patients lost to follow-up.
but the exact length of time was not measured.

The authors intended for their method to maximize the relative strengths of each Web site. Some Web sites provide a high volume of information but are not up-to-date, and vice versa. Frequently updated information is important for determining where a patient is, whereas a certain volume of information, including birthdates and names of relatives, is critical for verifying the identity of the patient, especially if the patient has a common name. In the authors’ experience, peoplefinders.com was effective at generating a list of potential locations for a patient, and whitepages.com was proficient at checking each location. This was because whitepages.com provided up-to-date information but had a low volume of data, whereas peoplefinders.com had a high volume of data but much of it was outdated (Table 2).

Based on their experience, the authors have 3 general recommendations for finding orthopedic patients for long-term outcomes research. Although they describe an alternate method, they recognize that the Internet changes rapidly, which will result in specific recommendations becoming outdated.

**Recommendation 1**

Identify the relative strengths and weaknesses of each intended source. Some Web sites provided a high volume of data and others are up-to-date but none were both. A common misconception is that one Web site will provide all the needed information, but this was not true for the current cohort. Instead, the authors addressed this problem by combining results from multiple Web sites to cross-check patient information.

**Recommendation 2**

Understand that the method by which one searches is often as important as the Web sites one chooses. For example, whitepages.com was only marginally effective, finding 12 patients using the King et al\(^3\) protocol, but it improved to 20 patients with the current authors’ new method. This was largely due to being able to narrow down, via peoplefinders.com, a patient’s most likely location. For patients with common names, this capability is essential. Age-specific strategies are an important part of one’s method. The authors’ success rate was due in part to the efficacy of the Social Security Death Index in locating deceased patients, which represented a significant portion of the study group. For pediatric orthopedic patients, age-appropriate social network sites, such as Facebook, may be more useful.

**Recommendation 3**

Have an awareness of the risk for privacy violations when searching online. The ease with which the researchers gained access to private and personal information was disquieting. Any private citizen willing to spend a small amount of money can quickly ascertain previous addresses, telephone numbers, family members’ names, and birthdates. This brings up serious ethical quandaries for re-

### Table 2

<table>
<thead>
<tr>
<th>Web Site</th>
<th>Source</th>
<th>Type</th>
<th>Datedness(^a)</th>
<th>Address &amp; Telephone</th>
<th>Birthdate</th>
<th>Other Data Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Patient Data Repository and Legacy.com(^2)</td>
<td>King et al(^1)</td>
<td>Social Security Death Index</td>
<td>n/a</td>
<td>No</td>
<td>Yes</td>
<td>Verification of death</td>
</tr>
<tr>
<td>Anywho.com(^d)</td>
<td>King et al(^1)</td>
<td>Free phone book Web site</td>
<td>Outdated</td>
<td>Yes</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>Whitepages.com(^e)</td>
<td>King et al(^1)</td>
<td>Free phone book Web site</td>
<td>Up-to-date</td>
<td>Yes</td>
<td>Occasionally</td>
<td>Relatives (occasionally)</td>
</tr>
<tr>
<td>People.yahoo.com</td>
<td>King et al(^1)</td>
<td>Free phone book Web site</td>
<td>Outdated</td>
<td>Yes</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>Peoplefinders.com</td>
<td>Supplemental</td>
<td>Paid search Web site</td>
<td>Outdated</td>
<td>Yes</td>
<td>Yes</td>
<td>Relatives, previous addresses</td>
</tr>
<tr>
<td>Spokeo.com</td>
<td>Supplemental</td>
<td>Paid search Web site</td>
<td>Outdated</td>
<td>Yes</td>
<td>Yes</td>
<td>Relatives, income level, occupation, race</td>
</tr>
<tr>
<td>Zabasearch.com</td>
<td>Supplemental</td>
<td>Free phone book Web site</td>
<td>Outdated</td>
<td>Yes</td>
<td>Occasionally</td>
<td>None</td>
</tr>
</tbody>
</table>

\(^a\)The current investigation used the King et al\(^1\) protocol. When Web sites drew from duplicate data sources, the authors selected 1 Web site to serve as a representative for the others. In addition, they added several supplemental online resources, including paid sites.

\(^b\)Decided by an estimate of the percentage of addresses provided by the site that were correct.

\(^c\)The Social Security Death Index is a government database, so the Web site of access is immaterial.

\(^d\)Anywho.com, addresses.com, superpages.com, and switchboard.com draw from duplicate data sources.

\(^e\)Whitepages.com and whowhere.com draw from duplicate data sources.
searchers, especially because the practice is not likely to be highly regulated by Institutional Review Boards. An alternate system may be to create a sort of national clearinghouse for contact information.

This study has limitations. The number of patients lost to follow-up was small, and comparisons between the easy-to-find and hard-to-find patients are limited given the low volume of participants. In addition, the authors did not conduct a comprehensive review of all potential search Web sites and cannot claim to have found the best online resources. Finally, the authors only examined 1 population.

Future studies would be well-served to compare 2 or more cohorts with differing follow-up periods or surgical procedures. Nevertheless, through experimentation, the authors attempted to develop the framework of an updated and effective protocol for locating patients.

**Conclusion**

The data indicate that patients lost to follow-up can be found using the Internet with a high degree of success despite a lengthy period of no contact. The authors were able to find 74% of their patients by creating a new protocol. Searching on the Internet requires a judicious use of sources, a carefully planned method, and awareness of privacy violations. However, these concerns considered, the Internet can be an effective tool for long-term outcomes research.

**References**