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Social Media as a Medical Survey Research Recruitment Tool: Examining Patient Experience with Inferior Vena Cava Filters

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CERTIFICATE OF APPROVAL

This is to certify that the Master's Capstone Project of

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"Social Media as a Medical Survey Research Recruitment Tool:
Examining Patient Experience with Inferior Vena Cava Filters"

Has been approved

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Table of Contents

Abstract

Objective:

Social Media offers the ability to quickly disseminate information to a large and diverse population of Internet users. The purpose of this study was to examine the use of social media for recruitment of patients with a history of an Inferior Vena Cava Filter (IVCF). The secondary goals were assessment of the prevalence of pain attributed to having an IVCF in place and to gauge patient understanding of follow-up after filter placement.

Materials and Methods:

A website was created to host a 12 question online survey. Patients were recruited via social media through posts on Twitter, Facebook, Reddit, and patient support group websites. A control cohort of patients were identified through traditional chart review and recruited via an email containing a link to the survey.

Results:

One hundred thirty three people consented to participate, of which 118 eligible respondents completed the survey. Seventy-seven responses came from social media and 41 from the control cohort. Prevalence of pain attributed to having an IVCF was 24%. Over 40% of patients with an IVC filter are unsure of the need for follow-up.

Conclusions:

Social media provides a low cost method to recruit a diverse cohort of survey respondents for clinical research. Almost a quarter of patients reported pain that they attribute to IVCFs, which should lead to increased awareness and further study. In addition, there continues to be room for improvement with long-term management of IVCFs and IVCF retrieval, as over 40% of patients are unsure of what to do about their implant.

Introduction

Social Media

Social media, in its variety of forms, allows people to quickly and easily share information and make connections through virtual communication networks. The rapid replication and transmission of information across these virtual networks has been compared to the infectious spread of a virus, with the audience acting as active and passive carriers.[1] With over 46% of the world's population now connected via the Internet, social media presents an opportunity to near instantaneously reach billions of people.

Medical applications of social media are steadily growing. Social media has helped patients and families with myriad conditions to connect and build support communities. Some of these communities, such as PatientsLikeMe, have leveraged their unique patient populations to assist researchers in finding cohorts of rare diseases, improve clinical trials through patient feedback, and study outcomes.[2,3] Dissemination of electronic surveys via social media has been used successfully to recruit patients for clinical research.[4,5] For rare disease conditions this presents an opportunity to gather enough patients to achieve a meaningful analysis of the aggregated data.

In comparison, traditional recruitment of patients for clinical studies has been done on an institutional level by identifying local patients that meet enrollment criteria through

often-tedious chart review. To increase cohort size and diminish regional bias in a study population, multi-institutional studies aggregate patients across different organizations to form as diverse a sample as possible. However, increased size and complexity of a multi-institutional study inherently comes with increased costs and organizational difficulties. Social media can be utilized for the same purpose with minimal additional costs and little to no increase in complexity.

Social media, with its ability to quickly disseminate information and reach both large and diverse population of patients as well as targeted populations, presents an intriguing method for enhancing the recruitment of patients to participate in clinical studies. The primary purpose of this study was to assess the utility in using social media to recruit a cohort of patients with a particular type of medical implant to complete an experiential electronic survey.

Inferior Vena Cava Filters

The medical device chosen for investigation was the Inferior Vena Cava Filter (IVCF). Inferior Vena Cava Filters are small metal devices that are placed into the inferior vena cava to prevent the movement of blood clots to the heart and lungs. The estimated total number of non-fatal, symptomatic venous thromboembolic events per year in the United States is ~600,000.[6] Placement of an IVCF is indicated in patients with acute venous thromboembolism who are unable to take anticoagulant medications or fail anticoagulant therapy.[7]

First used in 1968, the use of the device increased steadily from 2000/year in 1979 to ~49,000/year in 1999.[8,9] The first Food and Drug Administration (FDA) approved retrievable filters became available in 2003, and by 2006, 50% of the IVC filters placed were the retrievable type.[10] The use of IVCFs continued to rise before peaking in 2009 at 131,843 and subsequently decreasing to just under half that amount (63,445) by 2012.[11]

A number of complications related to IVCFs have been recognized including filter fracture, filter migration, filter tilting, strut penetration, and chronic pain.[7,12] Longer indwelling times have been associated with both filter related deep vein thrombosis and increase in strut penetration.[13] Despite recommendations for removal of retrievable filter as soon as medically reasonable, the actual removal rates for retrievable filters has been less than optimal, reported between 8.5% to 34%.[14,15] Reasons for suboptimal retrieval rates have been attributed to loss to follow-up, lack of follow-up, and patient non-compliance.[7]

The purpose of the electronic survey was to gain a better understanding of patient perceptions regarding their IVCF. First, do patients understand or have they been counseled by a physician that, when medically indicated, IVCF can and should be removed. Second, how prevalent are symptoms of chronic pain that patients attribute to the presence of an IVCF.

Materials and Methods

The Oregon Health & Science University (OHSU) Institutional Review Board granted an exemption to this project for human subjects research. A website was created to host an online patient-centered survey and collect the survey responses. The study population consisted of two groups, one recruited via social media, and the other recruited from traditional chart review. The survey was disseminated to the two cohorts through a clickable web link.

Survey

A survey was created consisting of twelve questions regarding the presence or history of an IVC filter, patient understanding of clinical planning for IVC filter retrieval/removal, and symptoms related to having an IVC filter in place (Appendix A). Depending on responses, participants were asked to complete up to eleven follow-up questions (Appendix B). Answers were required for all questions regarding IVC filters. The final questions related to gender, birth year, location (US state or international), and community setting (urban, suburban, rural) were optional.

Website

An interactive website was created using several open source tools to host the survey and record participant responses. The core of the website was constructed using Meteor, a Node.js based JavaScript development platform for quickly constructing web and mobile applications.[16] The Node.js environment allows a developer to code both

client and server applications in a single programming language, JavaScript.[17] The website pages were created using an HyperText Markup Language (HTML) framework called BootStrap, an open-source library of HTML, JavaScript, and Cascading Style Sheet (CSS) tools that allow rapid creation of uniform and intuitive user interfaces.[18] Finally, the survey responses were stored in MongoDB, an open-source database engine that uses a document-oriented data model to store information in collections.[19] MongoDB readily accepts information in JavaScript Object Notation (JSON), making information exchange between the client/server and database seamless.

The website consists of twenty-one total HTML templates. The survey questions make up the majority with twelve templates. The remaining templates are the home page, survey enrollment, consent page, survey page, thank you page, and an administrative page that allows users to dynamically view the survey responses. In addition, small templates are used for the sign in, sign out, and more information windows. The administrative page exists behind a login page, so only approved users can access the cumulative data. An "Export CSV" button also exists on the administrative page, which allows a user to download the aggregated data in a comma-separated value (CSV) format.

The website is formed as a series of stacked HTML/JavaScript templates, with each template representing an encapsulated and reusable element (Figure 1).

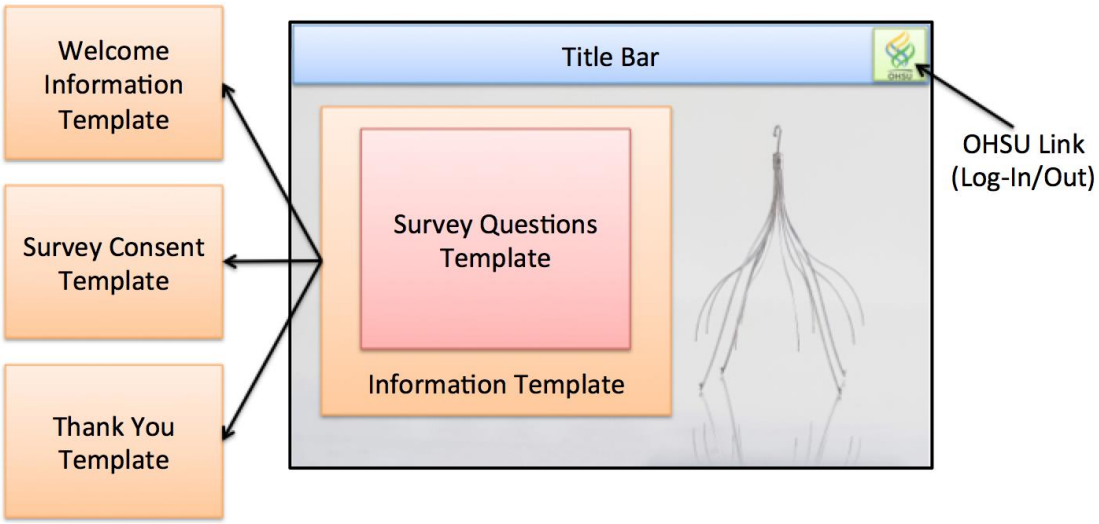

Figure 1. The template layout for a survey participant on the website.

On the website homepage there is a title/navigation bar across the top of the screen and a photograph of an IVCF along the right hand side of the screen. The left hand side of the screen is used by a series of HTML/JavaScript templates consisting of participant instructions and survey questions that guide a respondent through the questionnaire. The first template that is shown is a welcome screen with a message explaining the purpose of the survey, a note on the how long the survey should take, and a reassurance that all information collected is secure and confidential. Below are two buttons, one initiating the survey and a second for more information on IVC filters. The OHSU icon in the right upper hand corner links to the OHSU homepage, but also acts as a stealth link (using a right-click) to the login window to access the survey results (Figure 2).

Participant User Experience

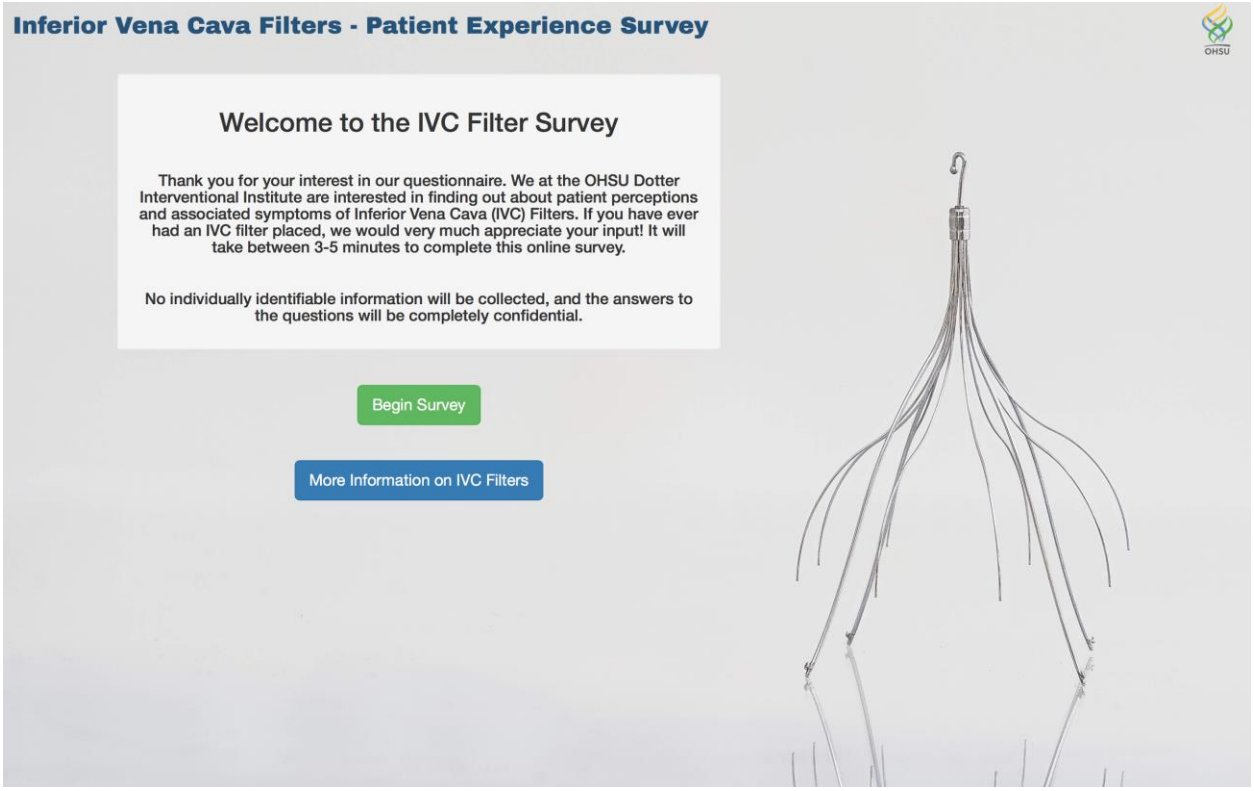

Figure 2. The survey homepage. Users can begin the survey, get more information on IVCF, or login to the researcher results page by right clicking on the OHSU icon.

The "More Information" button opens a popup window with a deeper explanation of the purpose, indications, and risks of having an IVC filter. When respondents choose the "Begin Survey" button they are then shown a short consent form that again gives an explanation of the purpose of the study, along with the names of the researches, and the title of the project. Users click "I agree" to participate in the survey.

Once a user has agreed to participation the survey begins. There are seven question/answer response types:

- Yes - No
- Yes - No - I Don't Know (Figure 3)

- Timing: < 1 month, 1 to 6 months, 6 to 12 months, > 1 year, and I Don't Know
- Symptoms (mark all that apply): Ringing in the Ears, Blood Clots, Pain, Headaches, and Stomach Upset
- Pain Location (mark all that apply): Back Pain, Stomach Pain, Chest Pain, Other
- Pain Severity: 1 - 10
- Demographics

Figure 3. One of the survey questions.

The demographics questions consisted of gender, birth year, community setting (rural, suburban, urban), and State (all fifty states with an added category of international for people located outside the United States). The demographics question (Figure 4) was the only question that survey respondents were allowed to skip.

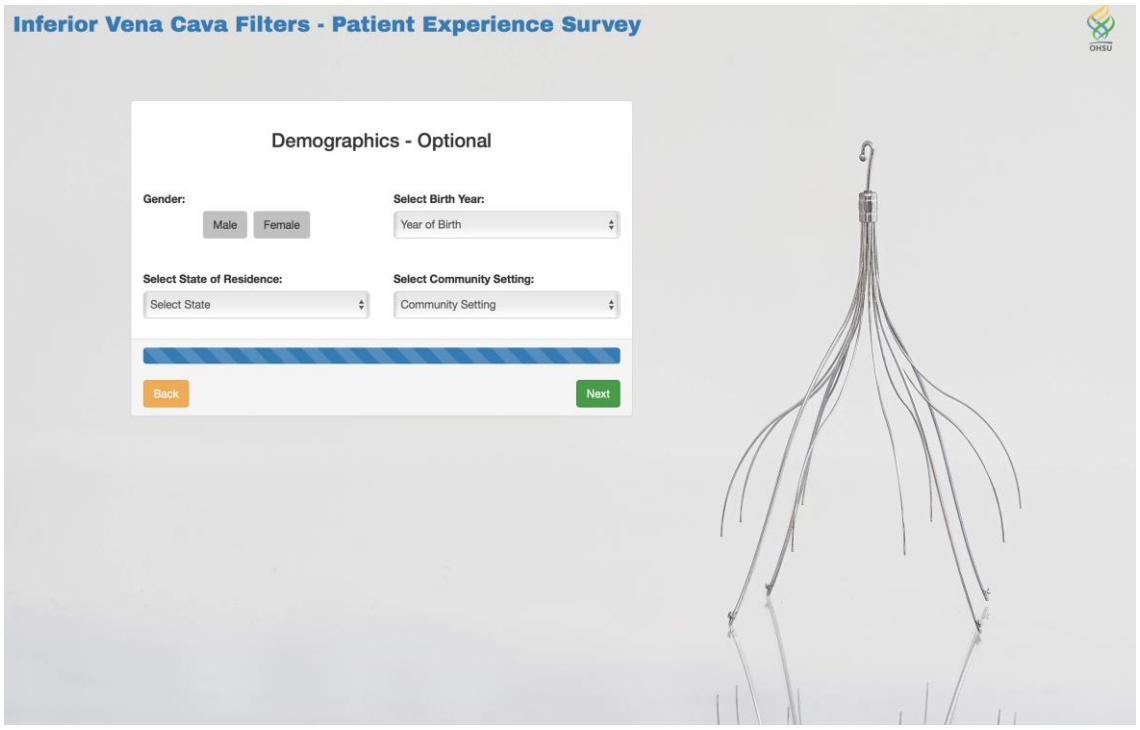

Figure 4. The demographics questions.

The respondent is then shown a summary of all their answers and could choose to go back and change any response or completely start over (Figure 5).

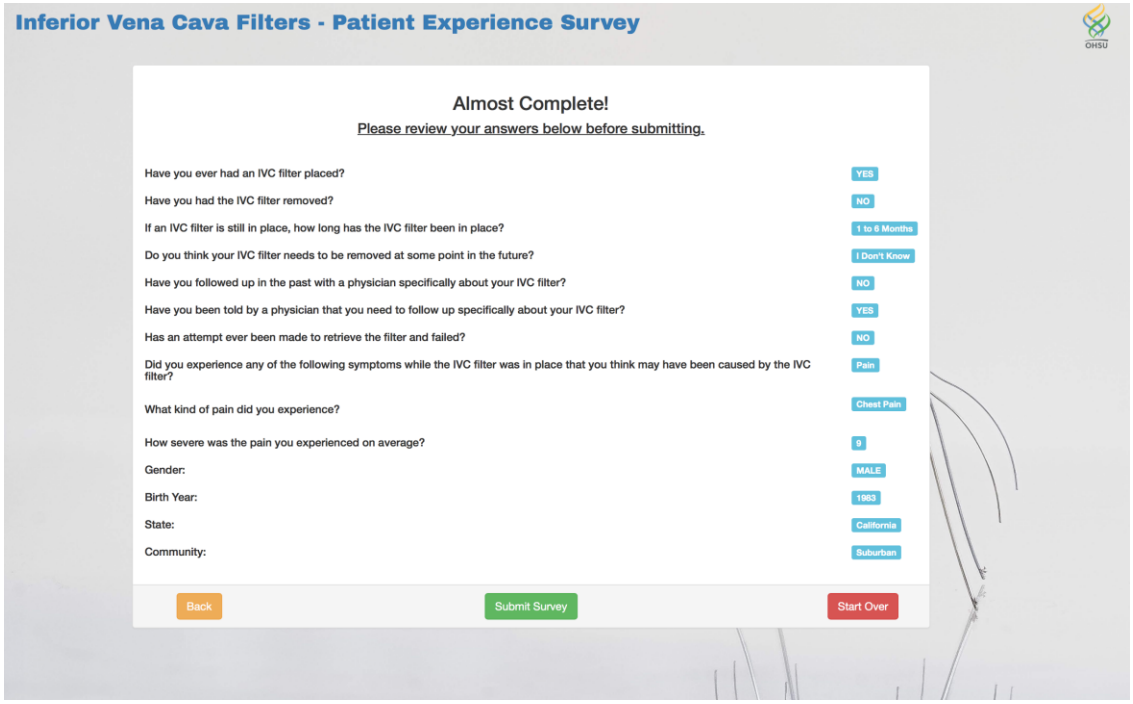

Figure 5. Answer summary. Participants can view all their answers and choose to submit the survey.

If a user chooses to "Submit Survey" they are then taken to a Thank You page with another "More Information" link, this time taking the user to the homepage of the OHSU IVC Filter Clinic (Figure 6).

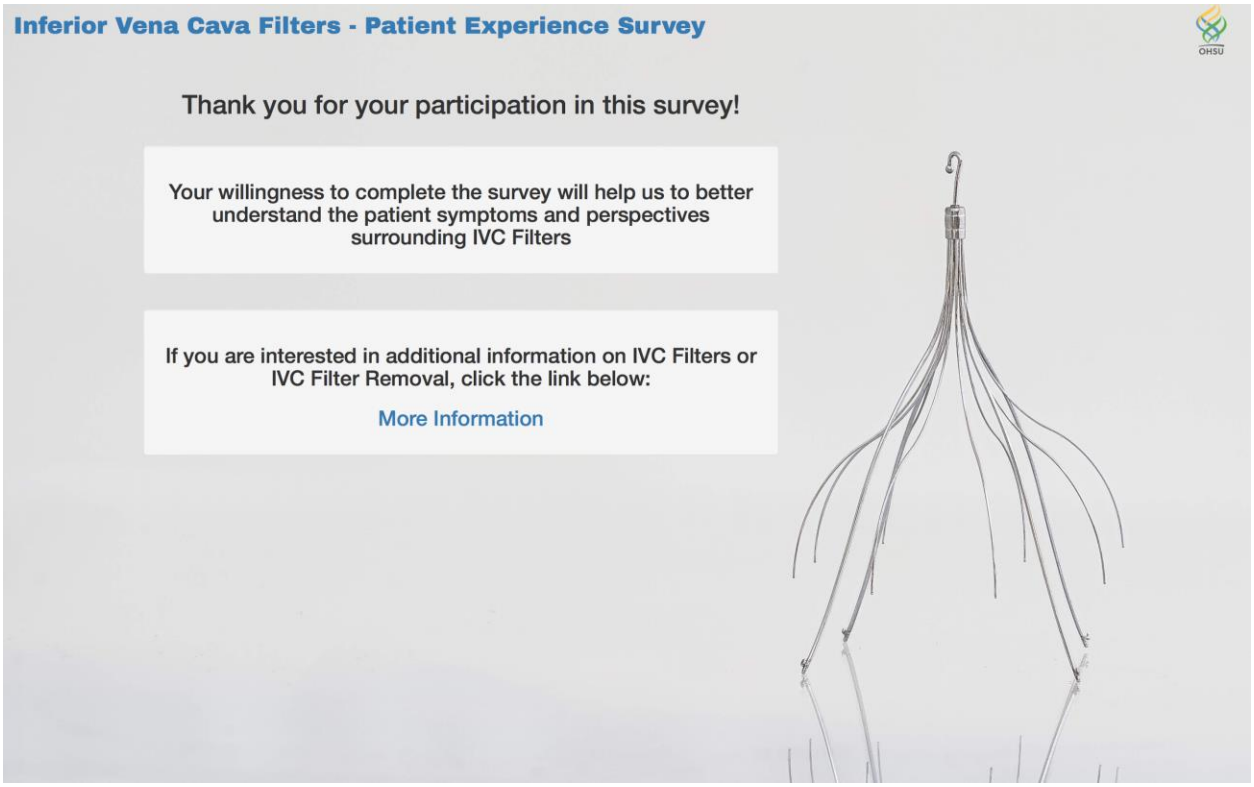

Figure 6. Thank You page shown to users after they complete the survey.

Researcher User Experience

Researchers have the ability to log in to view the survey results page. Once a user securely logs in, the homepage is replaced with a results page that shows the number of total survey responses as well as a dynamic table that allows the user to browse each response. In addition, there is an "Export" button that initiates the download of the data into a comma-separated value format (Figure 7). Clicking on the OHSU icon again, once logged in, allows the user to then log out.

Inferior Vena Cava Filters - Patient Experience Survey

Total number of surveys: 133

Survey Results — Export CSV

Linked From	Consent	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Birth Year	State	Community Type	Date/Time Submitted
fvlfb/nbca	I AGREE																
fbtcs	I AGREE																
ohsu	I AGREE																
ohsu	I AGREE	YES	YES	1 to 6 Months									FEMALE	1948	Washington	Rural	Tue May 02 2017 07:24:21 GMT-0700 (PDT)
fbtcs	I AGREE	YES	YES	1 to 6 Months									FEMALE	1953	Utah	Rural	Sun Apr 30 2017 06:46:17 GMT-0700 (PDT)
fbifsg	I AGREE	YES	NO		> 1 Year	YES	YES		YES				FEMALE	1985	New York	Urban	Mon Jun 05 2017 19:43:29 GMT-0700 (PDT)
reddit	I AGREE	YES	YES	1 to 6 Months									FEMALE	1989	Wisconsin	Rural	Wed Dec 28 2016 14:54:53 GMT-0800 (PST)
fvlfb/nbca	I AGREE	YES	NO		> 1 Year	YES	YES		YES	Stomach Upset							
fvlfb/nbca	I AGREE	YES	YES	1 to 6 Months						Blood Clot Pain Stomach Upset	Back Pain Stomach Pain	8	FEMALE	1982	West Virginia	Rural	Tue Feb 21 2017 11:26:08 GMT-0800 (PST)
reddit	I AGREE	YES	NO		> 1 Year	NO	NO	NO	NO				MALE	1983	Ohio	Suburban	Tue Feb 21 2017 21:32:25 GMT-0800 (PST)
ohsu	I AGREE	YES	YES	1 to 6 Months									FEMALE	1980	Washington	Urban	Sat May 06 2017 10:28:27 GMT-0700 (PDT)

Figure 7. The researcher results page that allows a user to browse and download the results. Only users with a login can view this page.

Recruitment

Two recruitment arms of the study were designed. The primary purpose of this research project was to test the utility of using social media for patient recruitment, so the testing arm is the social media cohort. For comparison, a control cohort was assembled using a traditional chart-review method to identify appropriate patients.

Social Media Cohort

Ten organizations and online social media support groups were identified with patient populations likely to include patients with a history of IVC filter placement. These organizations and groups were found by doing a series of web searches using Google, Facebook, Twitter, and Reddit. Only one dedicated IVC Filter support group was found. The remaining organizations and groups identified were associated with blood clots and hematologic disorders, as both provide indications for IVC Filter placement. The social media groups we contacted and their total followers can be seen in Table 1.

Group Name	Social Media	Total Followers
ClotSurvivors, We Fought the Clot!	Reddit	591
World Thrombosis Day!	Facebook, Twitter	7,995
Facebook: Factor V Leiden Support Group	Facebook	1088
National Blood Clot Alliance: Stop the Clot	Facebook, Twitter, Webpage	13,062
Facebook: The Clot Spot	Facebook	9
Facebook: IVC Filter Support Group	Facebook	100
North American Thrombosis Forum	Facebook, Twitter	N/A
Facebook: Deep Vein Thrombosis	Facebook	N/A
Patients Like Me - Research	Webpage	N/A
Von-Willibrand Disease Support Group	Webpage	N/A
Total		22,845

Table 1. Social media organizations contacted for survey promotion. Sites with N/A listed for number of followers either did not disclose their size or did not respond to inquiries for participation.

For organizations, the public relations representatives were contacted via email and asked to post the survey link to their social media accounts. For Facebook Patient

Support Groups and Reddit Forums, the group/forum administrator was contacted using the social media website and asked for permission to post the link to users. When allowed, a reminder link was posted 2-4 weeks after the original message.

Each organization and group was given a unique URL such that the social media source a participant used could be identified. The social media platforms that were used were:

- Reddit - A forum-based social news aggregator where users post, discuss, and vote on shared content
- Facebook - A social media community where users can share and comment on text, images, websites, and video
- Twitter - A social network where users interact with "tweets", individual messages that are restricted to 140 characters
- Website - Individual website for the organization or support group

Control Cohort

The control arm was comprised of a single institutional patient cohort assembled using manual chart review of patient records for patients with history of IVC filter placement. Beginning in 2011, every patient who had an IVC Filter placed by Interventional Radiology at Oregon Health & Science University was recorded in a dedicated patient list within the Epic EHR (Epic, Inc. Verona, WI). These lists were maintained for the purposes of clinical follow-up and scheduling of IVC Filter retrieval procedures.

Patient email addresses were obtained from the demographics section of each patient's chart in the EHR. The addresses were collected using the University's secure email system (Outlook, Microsoft Inc., Redmond, WA) and an email enrollment letter (see Appendix E) was sent to all identified email addresses using the blind carbon-copy (BCC) function of the email system. Care was taken to preserve the confidentiality of all clinic patients. The initial invite was sent on May 1, 2017 with a reminder email sent on June 5, 2017.

Analysis

Summary and statistical analysis of the survey response data was performed using STATA 14.2 (StataCorp, College Station, TX). Numerical measures were summarized as median (min – max), and categorical variables were demonstrated as frequency (percentage). Chi-square test was used to compare prevalence of IVC filter-attributed pain and the patient’s understanding of the need for IVC filter retrieval among categories of different factors. For this purpose, 2-by-2 or higher order tables were set up for each variable. Expected frequencies were calculated for each cell of the tables, and in cases that >20% of the cells in the table had expected frequencies < 5, Fischer’s exact test was used instead.

Results

Social Media Cohort

Six of the ten organizations and social media groups responded to our request to post a link to the online survey. One Facebook group administrator removed the link after 12 hours due to unspecified complaints from some of the group members. One organization with both Facebook and Twitter presence posted the link for our original request but did not respond to a request to post a reminder.

Group Name	Social Media	Responses	Rate
ClotSurvivors, We Fought the Clot!	Reddit	13	2%
World Thrombosis Day!	Facebook, Twitter	4	0.05%
Facebook: Factor V Leiden Support Group	Facebook	1	0.09%
National Blood Clot Alliance:	Facebook, Twitter, Webpage	50	0.4%
Facebook: The Clot Spot	Facebook	4	44%
Facebook: IVC Filter Support Group	Facebook	5	5%
Total		77	0.34%

Table 2. Social Media responses by organization. Response rate was calculated from total "followers" or group members from Table 1 above.

In total there were 77 responses from participants who navigated to the survey website from a social media link. With a total potential audience of 22,845 social media contacts, the response rate for the survey was 0.34%. Eleven patients gave only partial (n = 7) or no (n = 4) answers to questions in the optional demographics section.

Control Cohort

There were 375 total patients in the EHR list maintained for clinical follow-up. Seventy-five of those patients were deceased and eliminated from the chart review. In the remaining 300 patients, 132 had an email address documented within the demographics section of the EHR. Twelve emails bounced back because the email addresses were incorrect or no longer working. Two additional patients were reported deceased by their next of kin. This resulted in a total viable email cohort of 118 patients.

Forty-one patients responded to the email for a total response rate of 35%. One person opted not to complete any answers in the demographics questions while another omitted only the gender question.

Survey Responses

A total of 133 surveys were initiated via web link to the survey website. While the website and survey can technically be discovered by web search, all responses came from either the social media recruitment posts or from the link emailed to the control cohort of OHSU IVC Filter Clinic Patients. Fourteen surveys were not officially submitted, however four of these had otherwise been completed in entirety and are included in the analysis. Ten survey respondents reported never having an IVC filter placed (8 social media, 2 control) and were considered ineligible for the survey. In addition, three surveys were started but left completely blank and two surveys were only partially completed. All fifteen of these surveys were excluded from analysis. Figure 8 shows the breakdown of survey responses.

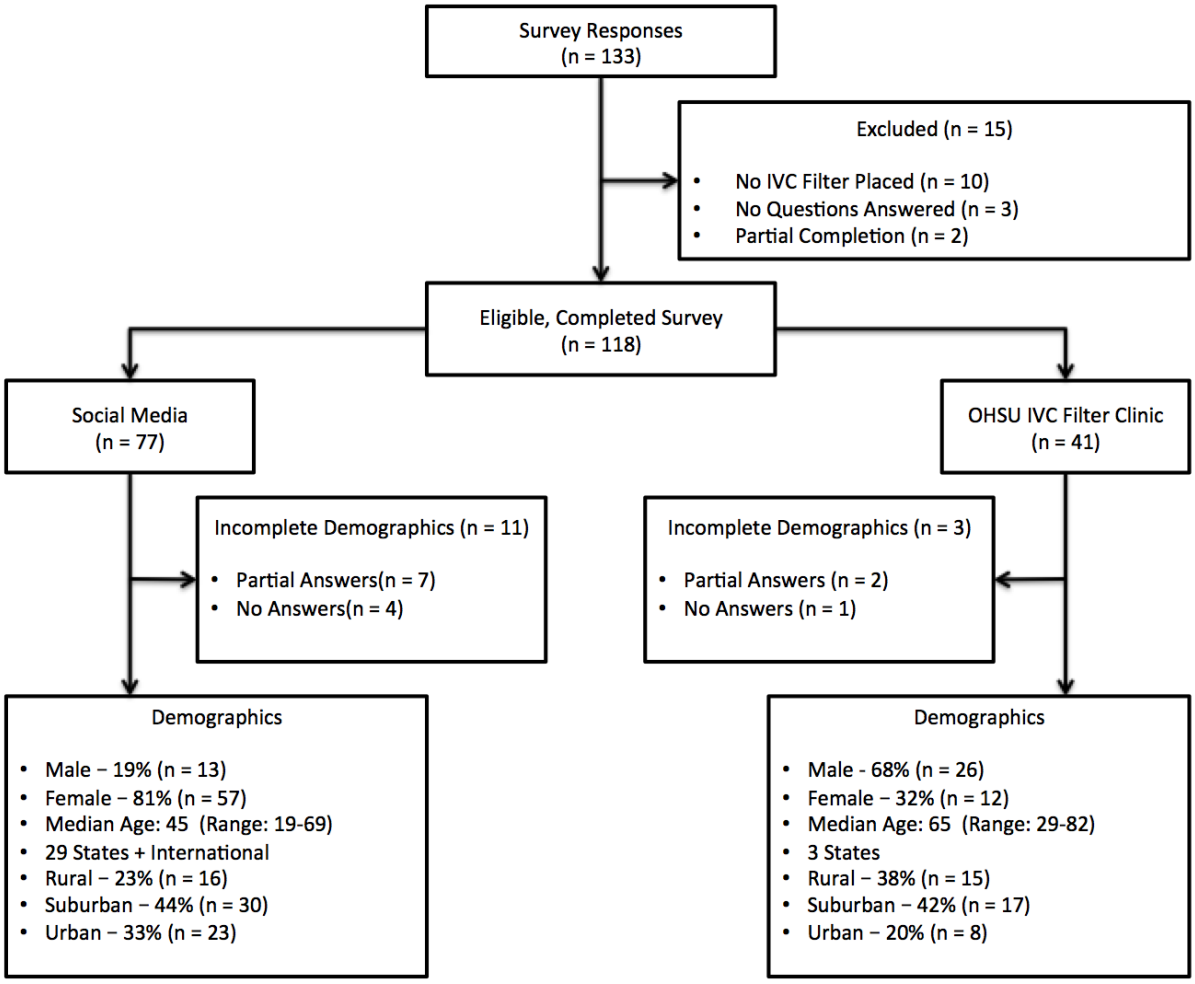

Figure 8. Examination of the survey responses, with focus on demographics compared between the cohorts.

Inferior Vena Cava Filters: Patient Perception of Pain

All eligible patients who completed surveys were included in the Pain Perception analysis (n = 118). Median age of the respondents was 49 (range: 19 – 82) years, and 69 (58.0%) of them were females. Seven patients had the IVC in place for < 1 month (5.9%), and 48 cases had it in place for > 1 year (40.3%). The majority of the respondents had their procedure done in United State (85.7%). Community type was rural (26.0%), urban (26.0%) and suburban (39.5%).

A total of 28 patients (24%) reported symptoms of pain, which they perceived as originating from the presence of an IVCF. The median severity score for all participants with pain was 7 (StDev: 2, Range: 3 - 10). Patients most frequently localized the pain to a combination of chest, stomach, back, or other (n = 11). In patients that reported only a single pain location, chest pain was the most common (n = 6), followed by stomach and other (n = 4), and then back pain (n= 3). However, when the pain locations are taken in total (combinations separated into the constituent locations) stomach (n = 12) was most frequent, followed closely by chest (n = 11), and back (n = 11), and then other (n = 7). Figure 9 shows the location, severity, and demographic split between the social media and control cohorts.

The prevalence of perceived pain was 30% in the social media group and only 12% in the control group. This difference in perceived pain between the cohorts was statistically significant (p = 0.035). In addition, the prevalence of IVC-related pain was 33.9% in respondents under 50 years old, and 13.3% in those ≥ 50 years (P = 0.008). Otherwise,

there was no statistically significant difference in prevalence of IVCF attributed pain by the subjects' gender, IVCF duration, US state or community setting (P = 0.989, 0.521, 0.683 and 0.688, respectively).

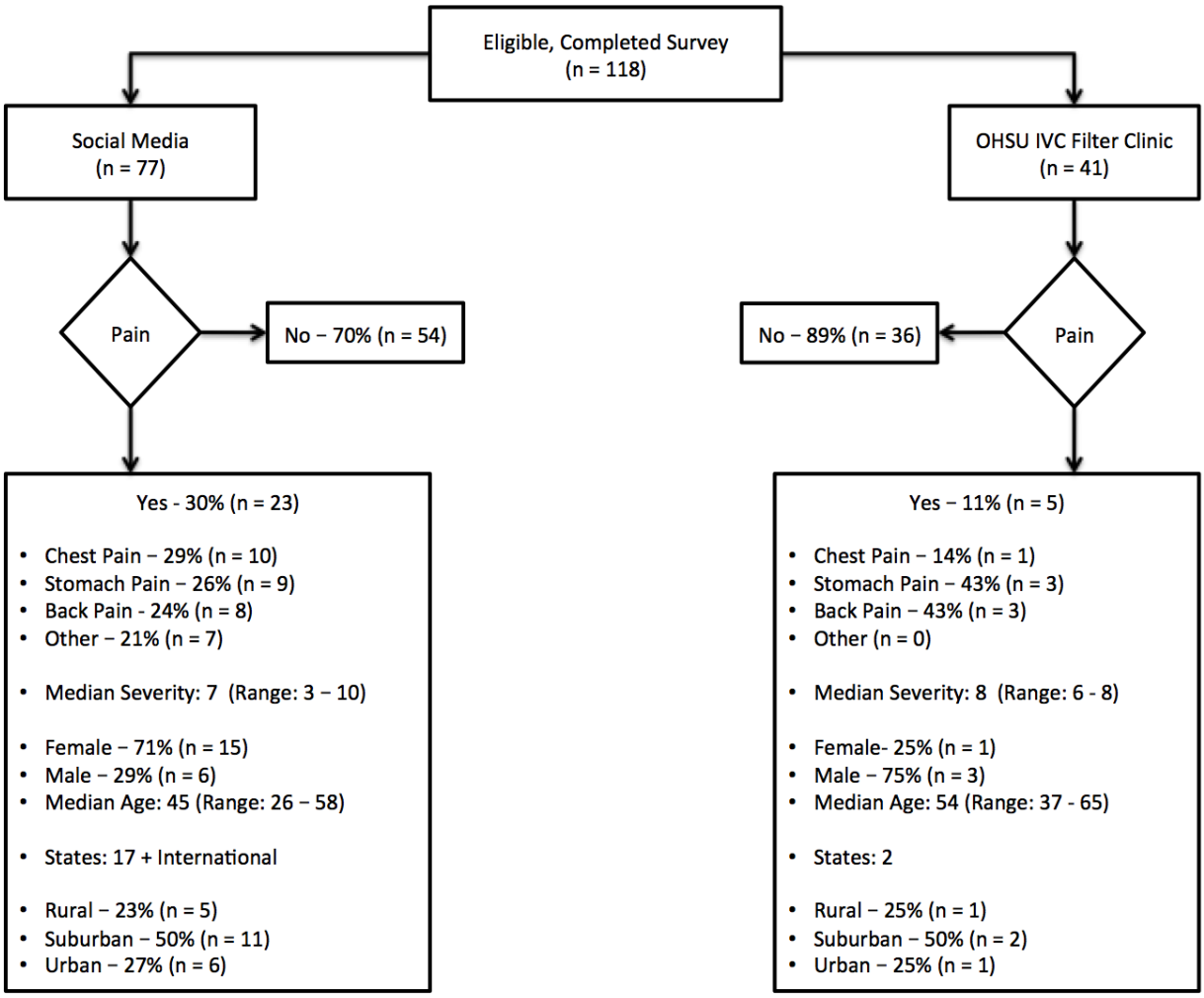

Figure 9. Analysis of patient perceived pain, as compared between the control and social media cohorts.

Inferior Vena Cava Filters: Patient Perception of Follow-Up

Two respondents from the control cohort reported never having an IVCF placed despite only being placed on the EHR follow-up list after receiving an IVCF. In total, 57 respondents answered questions regarding their understanding of the need for IVC filter retrieval. Median age was 47 years (range: 19 – 79), and 31 (54.4%) were females. The majority of these cases were referred from social media links (80.7%). Three cases had IVC filter for < 1 month (5.3%), 6 cases for 1 – 6 months (10.5%), and 44 cases for > 1 year (77.2%). Respondents were located in the United States in 45 cases (78.9%). Ten subjects had a previous failed attempt to retrieve the filter (17.5%). Regarding patient understanding of follow-up, 13 cases believed the filter should be removed (22.8%), 20 cases thought that the filter doesn't need to be removed (35.1%), and 24 cases were unsure if any follow-up needed to be performed (42.1%).

There was a significant difference in patient's perception for IVC filter removal between age groups. In respondents younger than 50 years of age, seven understood the need for filter removal (22.6%), 15 did not think that the filter needed to be removed (48.4%), and 9 cases were unsure if follow-up was needed (29.0%). In comparison, for those over 50 years old six wanted removal (23.1%), five didn't think it was necessary, (19.2%) and 15 were unsure (57.7%) (P = 0.045). There was no difference in the patient's' perception by gender, referral, IVCF duration, US State, or community setting (P = 0.149, 0.123, 0.788, 1.000 and 0.329, respectively).

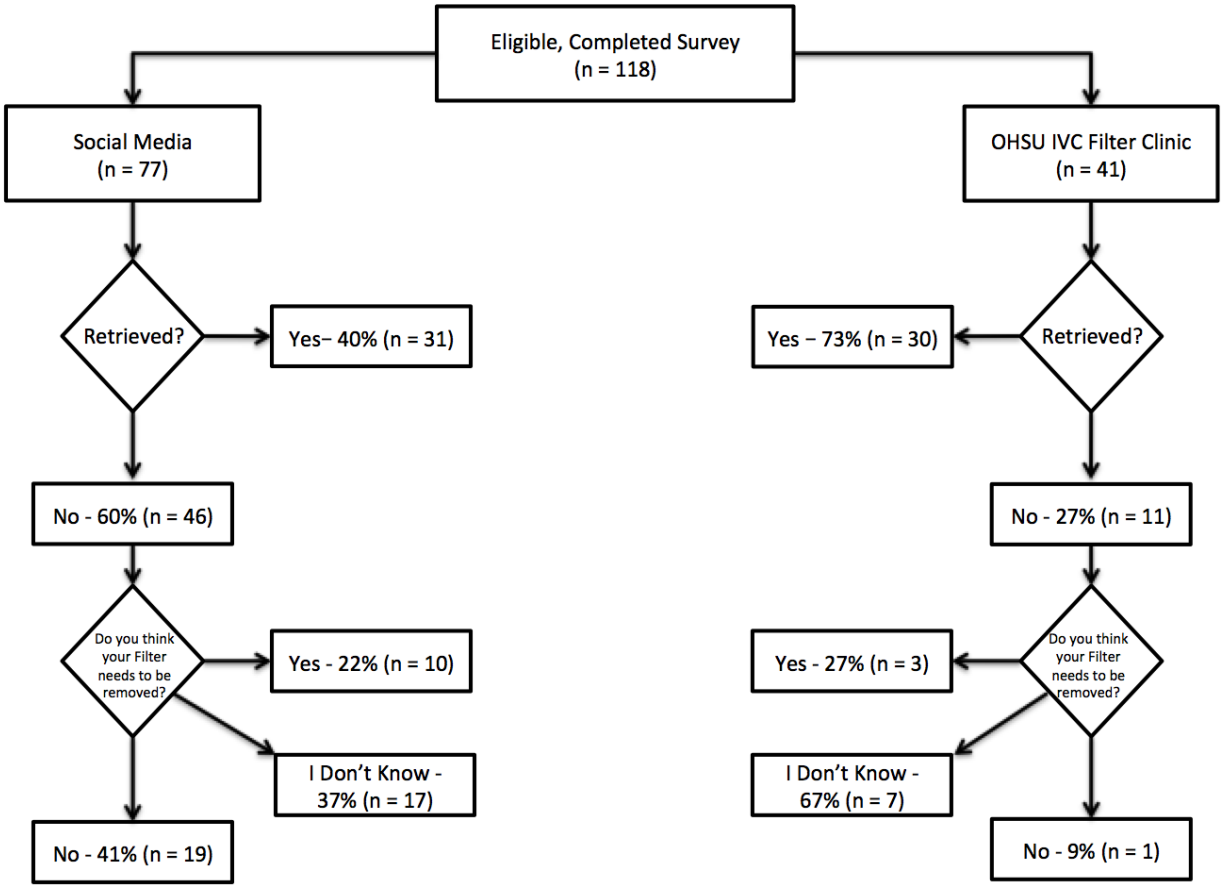

Figure 10. Patient perception of the need for IVCF removal.

Discussion

Social Media

The use of social media was effective in recruiting an appropriate cohort of IVCF patients to complete on online survey. Compared to similar online recruitment efforts we were able to obtain a reasonable number of respondents (n=88) from our social media based hyperlink dissemination. Few studies using social media for recruitment purposes report the overall response rate, possibly due to the difficulty in knowing how many members of the social media audience viewed the invitation. In one study of chronic disease performed via PatientsLikeMe the response rate was 24%.[2] The response rate for our survey was only 0.34%, based upon the large potential audience our social media posts could have reached. Our target population were those patients who had an IVCF implanted, however we discovered only one dedicated Facebook support group for IVCFs. The majority of our responses came from links sent out through various blood clot and hematologic disorder groups. While this proved to be effective, the incidence of blood clots is much higher than that of IVCF placement. As difficult as it is to estimate the number of patients we reached with our social media posts, it would be even harder to discern what proportion of the audience was comprised of our target population. Despite this, the completion rate for our web survey (88%) was also comparable to that of other clinical research social media surveys which have ranged from 78-88%.[4,20] In other words, eligible respondents completed with the survey once we were able to reach an appropriate candidate.

IVC Filters

The overall incidence of pain associated with IVCF is not known. At least 6 case reports have reported chronic pain in the chest, abdomen, or back as a symptom of long term IVCF presence.[12,21–25] In several of the case reports, removal of the filter was accompanied by resolution of the pain. This survey is the first to attempt to evaluate prevalence and characterize the pain attributed to IVCF presence. Almost a quarter of respondents (24%) reported isolated or a combination of pain symptoms involving the chest, abdomen, back, or other areas. The prevalence of pain was similar between both the social media and control cohorts. Chronic pain is common, affecting almost a third of all adults in the United States.[26] While this survey does not attempt to establish a causative relationship between the presence of an IVCF and pain symptoms, it is certainly worth noting that a significant amount of patients perceive and attribute pain to the presence of an IVCF. This information should help to raise awareness among physicians and inspire further study in order to gain a better understanding of this potential side effect. In addition, physicians should consider including this information when discussing treatments using an IVCF during the informed consent process to raise patient awareness as well.

Overall the rates of IVCF follow-up and retrieval were better for the control cohort than for those in the social media group. The prevalence of patients who are unsure about the need for follow-up of their IVCF remains high (42.1%). To control for bias in our patient recruitment, OHSU chart review was limited to just obtaining the email addresses of eligible patients. However, patients who receive permanent IVCFs are not

added to follow-up clinic list, so that could account for a portion of the difference between the control and social media data. The follow-up rate of the social media cohort is in line with the range reported in the literature, highlighting the fact that further works needs to be done by Interventional Radiologists and other specialties that place IVCFs to appropriately manage these patients after implantation. Follow-up and retrieval rates have improved as the idea of a dedicated clinic and resources devoted to aggressively following and managing outcomes has caught on. Reassuringly, the rates of follow-up and retrieval in our own OHSU IVCF Clinic are high, with the majority of respondents having their filter removed within the suggested time window.

Limitations

There are inherent limitations to the use of social media for clinical study recruitment. Recruitment to an online survey through advertisement is subject to response bias. If patients with IVCF related problems are more motivated to respond to the survey then the results will be skewed. By its nature, social media is predominantly used in a casual, social setting and users may not be interested in recruitment "advertisements" attempting to generate clicks on links to a survey, even if the goals is legitimate clinical research. However, support groups and patient advocacy organizations thrive on engaging their subscribers, so it is possible that appropriately targeted posts will result in high response and completion rates.

Unfortunately, the unique identifiers we used were organization or support group specific and did not capture the difference in response rates between Facebook and

Twitter for those organizations that utilize both social media networks. Adding a unique identifier for type of social media would have been helpful. Our dependence on the public relations directors for organizations and volunteer support group administrators also proved to be problematic. Several groups did not respond to our initial requests. Of those associations that did agree to send the link to members, one did not return our requests to send a reminder. In addition, a volunteer administrator of a support group removed the link within a day of the original post due to opposition from some of the other group members. Altogether, we were at the mercy of social media coordinators making it much harder to broadcast a unified and timely message with the survey link.

Due to the high incidence of blood clots and limited indications for IVCF placement, the majority of patients with venous thromboembolism never get an IVC filter. Similarly, followers of a particular social media group are not necessary sufferers of a disease. In fact, studies targeting patients via social media have attempted to recruit parents or siblings to answer questionnaires as well.[27]

The majority of patient respondents with an IVCF still in place also indicated the time period that the filter had been in place was greater than one year. We did not ask respondents to indicate what year their filter had been placed originally. Retrievable filters have only been available since 2003, and while their use compared to permanent filters has increased dramatically in the intervening years the proportion of permanent or retrievable filters in our cohort is not known. Patients with permanent filters would not need to follow-up with a physician to have their filter removed.

Conclusion

Social media is a unique platform for rapidly disseminating information to a broad and diverse population of people. Using social media is an effective method for recruitment of patients to clinical research surveys, however a targeted approach works best with social media groups in line with the question under study. Both social media and traditional recruitment methods were effective in this study. While the majority of responses came in through social media, the overall response ratio was much higher for the traditional single-institution clinical cohort. This is the first study that attempts to measure the prevalence of pain that patients attribute to the presence of an IVCF. A small but significant proportion of patients experience chronic pain that they attribute to the presence of an Inferior Vena Cava Filter. In addition, a significant proportion of patients with an IVCF in place are unsure of the need for clinical follow-up.

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Appendix A - Survey Questions

Question 1:
Have you ever had an IVC filter placed?
Yes -> Question 2
No -> Question 12

Question 2:
Have you had the IVC filter removed?
Yes -> Q.3
No -> Q.4

Question 3:
If your IVC filter was removed, how long was the IVC filter in place?
<1 month -> Question 9
1-6 months -> Question 9
6-12 months -> Question 9
>1 year -> Question 9

Question 4:
If an IVC filter is still in place, how long has the IVC filter been in place?
<1 month -> Question 5
1-6 months -> Question 5
6-12 months -> Question 5
>1 year -> Question 5

Question 5:
Do you think your IVC filter needs to be removed at some point in the future?
Yes -> Question 6
No -> Question 6
I Don't Know -> Question 6

Question 6:
Have you followed up in the past with a physician specifically about your IVC filter?
Yes -> Question 8
No -> Question 7

Question 7:
Have you been told by a physician that you need to follow up specifically about your IVC filter?

Yes	->	Question 8
No	->	Question 8

Question 8:
Has an attempt ever been made to retrieve the filter and failed?

Yes	->	Question 9
No	->	Question 9

Question 9:
Did you experience any of the following symptoms while the IVC filter was in place that you think may have been caused by the IVC filter (mark all that apply)?

Ringing in the ears	->	Question 12
Blood clots	->	Question 12
Pain	->	Question 10
Headaches	->	Question 12
Stomach upset	->	Question 12

Question 10:
Can you be more specific about the kind of pain you experienced?

Back pain	-> Question 11
Stomach pain	-> Question 11
Chest pain	-> Question 11
Other	-> Question 11

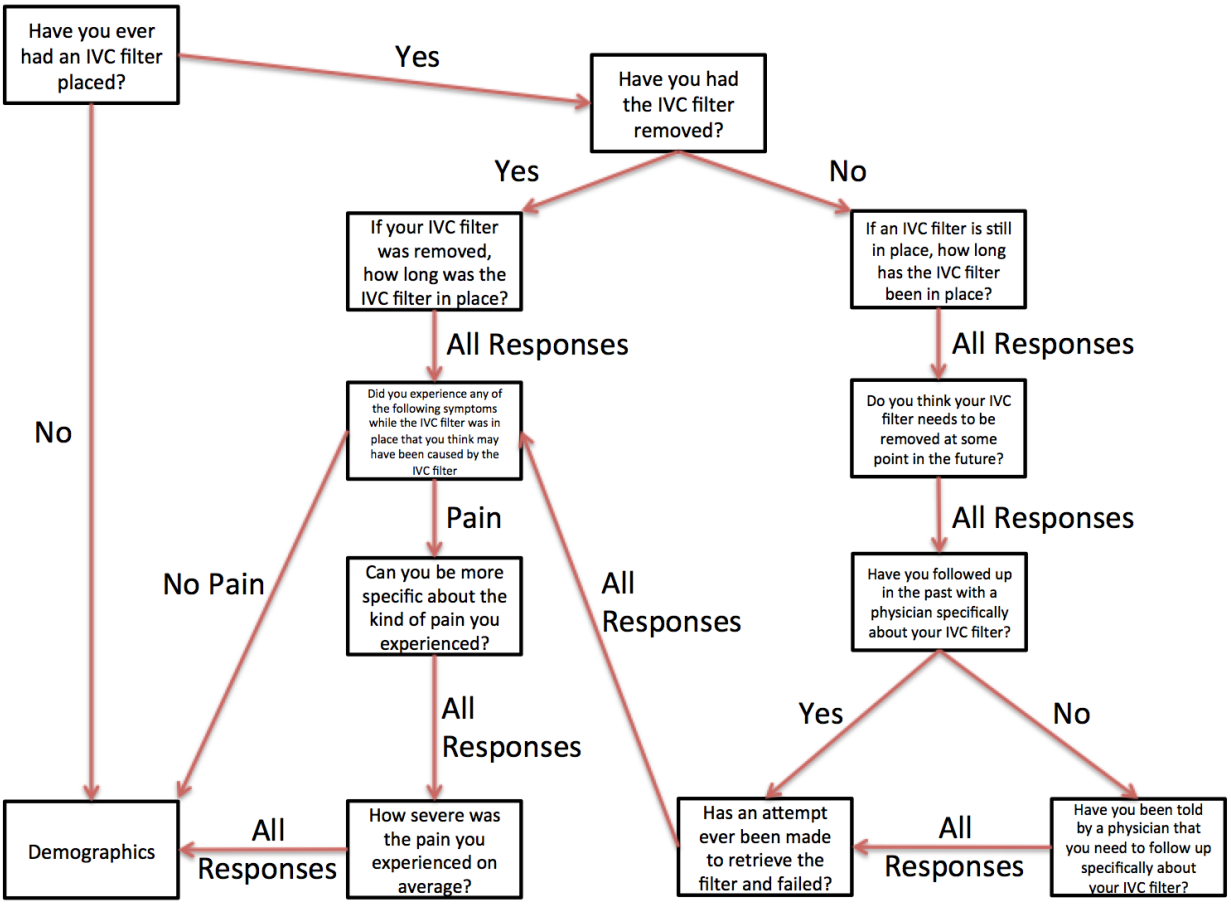
Question 11:
How severe was the pain you experienced on average? (1 - Mild pain, 10 Severe pain)

1	->	Question 12
2	->	Question 12
3	->	Question 12
4	->	Question 12
5	->	Question 12
6	->	Question 12
7	->	Question 12
8	->	Question 12
9	->	Question 12
10	->	Question 12

Question 12:
Demographics - Optional:

Gender	Birth Year	State	Community Setting
Male Female	Selected from year range (1901-1999)	US State (all 50 options) International	Urban Suburban Rural

Appendix B - Question Flowchart



Appendix C - More Information on IVC Filters

What is an IVC filter?

The inferior vena cava (IVC) is the largest vein in the body. It allows blood from the legs and pelvis to return to the heart. An IVC filter is a small metal device implanted within the IVC that is designed to prevent blood clots in the legs from travelling to the lungs, heart, or brain.

Why is an IVC filter placed?

An IVC filter is typically placed for a blood clot in the leg (Deep Vein Thrombosis (DVT)) or a blood clot in the lung (Pulmonary Embolism (PE)). Standard treatment is to start a blood thinning medication, also known as anticoagulation therapy . Some patients cannot be anticoagulated because of bleeding, trauma, surgery, or other high risk medical problems. Other patients may experience bleeding or progression of blood clots despite taking blood thinner medications. In those scenarios an IVC filter should be placed to protect against life threatening pulmonary embolism (PE).

Know the Risks:

During placement or retrieval of an IVC filter there is a small risk of bleeding or infection, occurring in about 1/1000 patients. Even less likely, a patient may develop a pneumothorax, separation of the lung from the chest wall. Filters may become severely tilted or penetrate the wall of the IVC causing injury to the vessel or nearby organs. Very rarely, some filters have been shown to fracture or move over time resulting in bowel,

heart, or lung injury and extremely rarely, death. Commonly, small clots become trapped or form within the filter. If a large clot develops in the IVC filter it can potentially cause obstruction of the IVC resulting in leg swelling, hyperpigmentation, or ulceration of the lower extremities. Long-term, IVC filters continue to protect against PE while in place, but have been associated with an increased risk of lower extremity deep vein thrombosis (DVT). There is a slight risk of allergic reaction or kidney injury related to the contrast material used during the procedures.

Appendix D - Social Media Websites

Group Name	Website
ClotSurvivors, We Fought the Clot!	https://www.reddit.com/r/ClotSurvivors
World Thrombosis Day!	http://www.worldthrombosisday.org
Facebook: Factor V Leiden Support Group	https://www.facebook.com/factorfiveleiden15
National Blood Clot Alliance: Stop the Clot	https://www.stoptheclot.org
Facebook: The Clot Spot	https://www.facebook.com/groups/1017727935010156
Facebook: IVC Filter Support Group	https://www.facebook.com/groups/IVCFilterSupportGroup
North American Thrombosis Forum	http://www.natfonline.org/patients/support-group/online-support-group
Facebook: Deep Vein Thrombosis	https://www.facebook.com/Deep-Vein-Thrombosis-632068940162341
Patients Like Me - Research	https://www.patientslikeme.com/research/faq
Von-Willibrand Disease Support Group	http://www.mdjunction.com/von-willebrand-disease

Appendix E - Patient Recruitment Letters

Initial Invitation Letter:

Dear Patient,

I am emailing you from the Interventional Radiology Department at Oregon Health and Science University. Our records indicate that you have or have had an Inferior Vena Cava (IVC) Filter placed or removed at OHSU. As part of our academic mission to continually improve patient care we are conducting a study of patient knowledge and symptoms related to IVC Filters.

We hope that you will consider participating and help us better understand your patient experience with an IVC Filter. This survey is completely anonymous and should take no more than 5 minutes to complete. No information gathered can be used to link back to the respondent. A reminder email will be sent in two weeks.

To complete the survey, please click the link below and follow the instructions on the website.

http://www.ivcfiltersurvey.com/ohsu

Thank you!

Reminder Letter:

Dear Patient,

This is a reminder email regarding our OHSU IVC Filter Survey. This will be the only reminder and the last email you will receive about this survey.

If you have already completed the survey, we appreciate your participation and apologize for the redundant email. If you have not yet completed the survey and wish to participate, please visit the link below and follow the instructions on the website:

http://www.ivcfiltersurvey.com/ohsu

This survey is completely anonymous and should take no more than 5 minutes to complete. No information gathered can be used to link back to the respondent. The Interventional Radiology Department at Oregon Health and Science University is continually trying improve patient care and we thank you for your time and consideration to help us achieve that goal.

Thank you!