



From Crowd to Bedside: Development of a Patient-Centered Informed Consent for Lung Cancer Surgery Using Social Media

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BACKGROUND

- An essential element of informed consent includes disclosure of all significant risks and benefits associated with the procedure, its alternatives, and in not receiving treatment.¹
- Yet patients' unmet information needs are among the highest negative post-operative experiences.^{2,3,4}
- A recent study investigating the patient experience in unsuccessful surgical procedures found that these patients felt unprepared for their treatment outcome and wished they had received more information regarding potential complications.²

HYPOTHESIS

Ultimately, we will test the hypothesize that by expanding informed consent to include real-world statements on post-operative limitations from patients who have undergone either a pulmonary sublobar resection or lobectomy, we will improve patients' understanding of the associated post-operative risks and potential long-term patient outcomes after lung cancer surgery.

OBJECTIVE

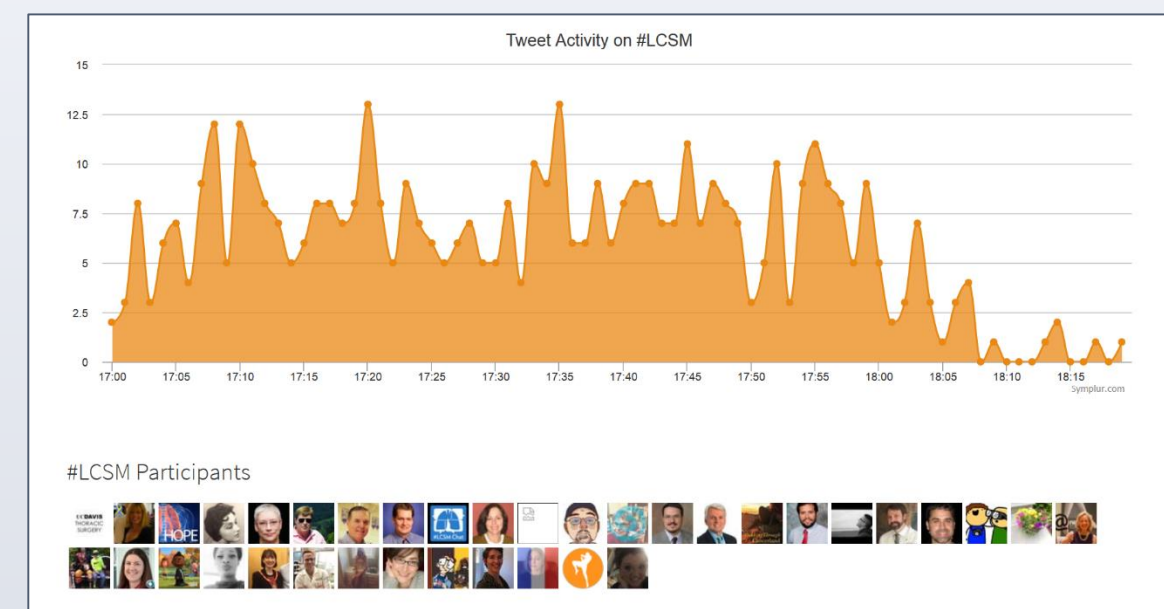
We describe the initial process of developing a patient-centered informed consent for lung cancer surgery.

METHODS

- On 6/18/15 utilizing the novel social media patient engagement platform, #LCSM Chat (Lung Cancer Social Media; lcsmchat.com), a Tweet Chat was held using the following questions as discussion points:
 - As a patient or caregiver, what do you wish you had known prior to lung cancer treatment?
 - As a healthcare provider, what do you wish your patients knew prior to lung cancer treatment?
 - What is the best way to get accurate information on potential outcomes to patients prior to treatment?
 - What barriers exist to getting this information to patients in a timely manner?
 - Would patient/caregiver testimonials as a patient-centered informed consent be helpful in conveying accurate & realistic outcomes?
- Tweet Chat participants were also asked to fill out a Survey Monkey based questionnaire.
- We performed content analysis of the Tweet Chat transcripts to identify important themes self-identified by lung cancer stakeholders as important.

RESULTS

Figure 1. 6/18/15 Tweet Chat Analytics



The Numbers

2,254,132 Impressions

473 Tweets

36 Participants

355 Avg. Tweets/Hour

13 Avg. Tweets/Participant

Figure 2. Sample Tweets

T1: Wish I'd understood the importance of getting a second opinion BEFORE starting treatment. Everything was a blur. #lcsm
Thu Jun 18 17:06:02 PDT 2015 - 4h, 53m

T1: Knowing what may happen what does happen after to can be different. threw away 4 cancer books before I realized it was my last buds #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

Wish I had known that small chemo side effects can pile up on one person making you very sick #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

ucd_chesthealth T2: As a healthcare provider, what do you wish your patients knew prior to #LungCancer treatment? #LCSM
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

julliangultron Undergoing surgery = boxing match -> you train hard for it and go in as fit as possible for best outcome #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

T2: From HCP perspective #LungCancer Rx includes providing #surgery, chemo, radiation treatment... #LCSM #lcschat
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

ucd_chesthealth T3: What is the best way to get accurate information on potential outcomes to patients prior to treatment? #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

T3: Multiple channels, multiple times, print, video, face to face patient and caregiver, interactive apps #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

T5: Would patient/caregiver testimonials as a #PatientCentered informed consent be helpful in conveying accurate & realistic outcomes? #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

@UCD_ChestHealth testimonials powerful on topics eg informed consent, shared dx, palliative care, financial counseling with your hope #lcsm
Thu Jun 18 17:04:02 PDT 2015 - 4h, 55m

Table 1 (Topic 1-3). Top Three Response Themes per Topic from the 6/18/15 #LCSM Tweet Chat

TOPIC 1: As a patient/caregiver, what do you wish you had known prior to lung cancer treatment?		TOPIC 2: As a healthcare provider, what do you wish your patients knew prior to lung cancer treatment?		TOPIC 3: What is the best way to get accurate information on potential outcomes to patients prior to treatment?	
RESPONSE THEMES	EXAMPLE STATEMENTS/CONCEPTS	RESPONSE THEMES	EXAMPLE STATEMENTS/CONCEPTS	RESPONSE THEMES	EXAMPLE STATEMENTS/CONCEPTS
1. Impact of Side Effects	"lobectomy was overwhelming pain"	1. Patient Pre-Op Optimization	"you train hard for it (surgery) and go in as fit as possible for best outcome"	1. Hybrid Approach	"multiple channels, multiple times, print, video, face to face"
2. Importance of Molecular Analysis of Tissue	"importance of tissue management for genetic testing"	2. Treatment is Trimodal	Involves surgery, chemotherapy, and radiation	2. Face-to-Face with Provider	e.g. office appointments with diagrams, nurse patient navigators
3. Patient Pre-Op Optimization	e.g. flu shot, patient conditioning	3. Patient Post-Op Optimization	e.g. spirometer use, exercise	3. Online Resources	e.g. social media, apps, websites

Table 2 (Q1-Q5). Survey Responses

The survey was designed, using qualitative data gathered from prior study Tweet Chats and in-person UC Davis Thoracic Surgery Patient Focus Groups, to capture the unmet needs and post-operative experiences of lung surgery patients.

Q1: List up to 5 questions regarding your recover after lung cancer surgery that you wish you had asked your doctor prior to surgery.

Respondent 1: How hard it is.

Respondent 1: How long it will take.

Respondent 1: Is it normal to complain.

Respondent 2: How long will it take to recover?

Respondent 2: Do I need a pulmonologist to help me with breathing?

Respondent 2: Will I need to do rehab after surgery?

Respondent 2: Whom do I call if I need help while I'm recovering?

Respondent 2: What will you be doing with my tissue?

Q2: List up to 5 post-operative complications you experienced and felt you were not prepared for.

Respondent 1: Pain.

Respondent 1: Nerve pain.

Respondent 2: Severe pain...had UL lobectomy and resected arteries.

Respondent 2: Trouble swallowing.

Respondent 2: Trouble breathing while lying flat.

Respondent 2: Pulmonary embolism due to necrosis to hip and femur.

Q3: Please complete the following statement:
After my lung cancer surgery, I can no longer....
(Ex: "I can no longer play an 18-hole round of golf, instead I play a 9-hole round.")

Respondent 1: play basketball.

Respondent 2: breathe without inhalers.

Q4: Please complete the following statement:
After my lung cancer surgery, I did not expect....
(Ex: "I did not expect my post-operative pain to continue for years.")

Respondent 1: nerve pain and numbness 17 years later.

Respondent 2: to not be able to breathe without inhalers.

Q5: List up to 5 recovery tips that you would like to share with future lung cancer patients. (Ex: Walk often, post-recovery bra support for women, etc...)

Respondent 1: Walk right away.

Respondent 1: Do your chest pt.

Respondent 1: Listen to your nurses.

Respondent 2: Walk very short distances right away...around the dining room table.

Respondent 2: Eat small meals often.

Respondent 2: Call your physician before things become an emergency.

Respondent 2: Have a pulmonologist involved in your care.

- 2 participants completed the survey.

DISCUSSION

- This study provides valuable multi-stakeholder insight into the lung cancer patient post-operative experience.
- In regards to the additional survey, there were only two respondents despite 36 active Tweet Chat participants, and 2,254,132 passive impressions.
 - This low response rate speaks to the limitations of using social media as a way to collect data, i.e. many impressions, fewer interactions.

FUTURE GOALS

- Continue to administer survey (Table 2) to UC Davis post-operative lung cancer surgery patients.
- With the assistance of a UC Davis Thoracic Surgery Community Stakeholder Advisory Panel, translate survey responses into a novel patient-centered consent form for patients undergoing pulmonary resection.
- Perform a comparative-effectiveness analysis comparing those receiving the standard-of-care consent to those receiving the standard-of-care consent plus the patient-centered consent form, and determine any differences in patient satisfaction and decision regret.

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ACKNOWLEDGEMENTS

- Supported by:
- UCD SOM Medical Student Research Fellowship
 - PCORI Pipeline to Proposal Tier II