

Patient Advocate for Antibiotic Stewardship Engagement Session

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Objective

Patient Advocate for Antibiotic Stewardship

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Accurately identifying infections is important to giving patients the correct treatment. Misdiagnosis– or incorrectly identifying an infection – can harm patients when providers give them antibiotics they do not need. Researchers at the University of Utah need input to inform a tool that helps measure hospital grades among patients diagnosed with pneumonia or a urinary tract infection. Topics that will be discussed include: how patients or their family member were diagnosed, what treatment patients or their family member received, and how hospital diagnosis and treatment may inform future medical decisions.

Questions that will be discussed during the Engagement Session:

1. How did your or your family member's doctor determine that you or your family member had pneumonia / UTI?
 - a. What additional information about the diagnosis do you wish you had been told by the doctor?
 - b. What additional information about the antibiotic treatment do you wish you had been told by the doctor?
2. What do you think are the main benefits of antibiotics? What do you think are the main risks of antibiotics?
3. What do you think overdiagnosis means? What do you think under-diagnosis means?
4. How do you know if a hospital is doing a good job?
 - a. If hospitals were rated based on how well they diagnose patients with infection, how would that make you feel?
 - b. If hospitals were rated based on how well they use antibiotics, how would that make you feel?
 - c. How would publicly available information about how well a hospital provides care influence your medical care choices?

Demographics

Due to COVID-19 physical distancing guidelines, this Engagement Session was held remotely on Zoom with (7) participants. Fifty-seven individuals completed a pre-screener with basic demographic information and were recruited through the following resources: CCET Past Participant Directory, social media posts, flyers, friends, investigator contacts and word of mouth.

Disclosed demographic information from the (7) selected participants includes the following:

- Age:
 - 34-98 years old
 - Mean: 70
- Gender identity and expression:
 - (3) Man / Male / Masc.
 - (4) Woman / Female / Femme
- Race / Ethnicity:
 - (5) White or European
 - (1) African American/Black
 - (1) Native Hawaiian/ Pacific Islander
- Total annual household income:
 - (1) \$25,000 - \$39,999
 - (2) \$50,000 - \$74,999
 - (4) Not provided
- Religious affiliation:
 - (2) Agnostic
 - (2) Christian
 - (3) Not provided
- Highest level of education:
 - (2) Bachelor's Degree
 - (1) Master's Degree
 - (4) Not provided
- How would you describe the area where you live?
 - (1) Suburban
 - (3) Urban
 - (4) Not provided
- Number of people in your family household:
 - (2) One
 - (1) Two
 - (1) Four
 - (3) Not provided

Transcript

** Indicates that more than one participant agrees with this statement*

1. How did you or your family member's doctor determine that you or your family member had pneumonia / UTI?

- a. Diagnosis made by chest Xray**
 - a. Symptoms were slight cough
 - b. inability to breathe probably determined diagnosis
- b. Hospitalized
 - a. Transferred from Emergency Room
 - b. Severe enough to be admitted to hospital for 7 days and 3 days after in acute care
 - c. Comorbidities existed and was on dialysis

1. Unsure of which comorbidity caused the outcome of diagnosis
- c. Hospitalized for surgery due to broken leg
 - a. Readmitted after additional accident with broken ribs and punctured lung, chest tube fell out and was leaking, woke up not being able to breathe
 - b. Severely sick
 - c. Pain assessed
 1. Hard to recall how diagnosis came about
 - d. Hospitalist was extremely helpful
- d. Urine test*
- e. Blood tests*
 - a. Several different labs
- f. Acute care appointment
 - a. Diagnosed with respiratory infection and prescribed cough medicine
 - b. Coughed blood
 - c. Lab work came back positive for pneumonia, put on CPAP machine
 - d. Readmitted to hospital, put on antibiotics and steroids
 - e. Contradictory diagnosis from different doctors
 - f. Referred to rheumatologist, more labs to confirm pneumonia
 - g. Infectious disease doctor was seen and treated with anti-fungal medication and antibiotic
 - h. Was on multiple medications with multiple side effects
 - i. Negative experience
- g. Emergency room visit
 - a. Diagnosed with dehydration
 - b. Hours later received call from doctor with test results
 1. Blood panel done
 2. Urine test revealed high creatinine levels and a UTI
 - c. Followed for two days and sent to hospital
 - d. Back pain managed with Tylenol and Tramadol
 - e. Many post-discharge follow ups and updates
 - f. Escalation from Emergency Room to Intensive Care Unit
 1. Request information as to how and why the transfer
 2. In emergency situations, providers were quick to communicate and pick up more subtleties
- h. Unresponsive in Rehab facility
 - a. Low Oxygen saturation
 - b. Diagnosed with UTI and prescribed antibiotics
- i. Had to do own research to determine if diagnosis was correct
- j. Agreed with doctor's diagnosis*

2. What do you think are the main benefits of antibiotics? What do you think are the main risks of antibiotics?

Benefits:

- a. Clears up infection quickly
- b. Lower symptoms quickly
- c. Guards against reoccurrence and reinfection*
- d. Beneficial in severe situation*
- e. Required due to severity of diagnosis
- f. When given adequate information on how to take antibiotics and take with pro- and pre- biotics had a better experience

Risks/Concerns:

- a. Disrupts gut microbiome, causing stomach issues*
- b. Unknown allergies to medication
- c. Overuse of antibiotics results in infectious strains to become more resistant to treatment
- d. More focus should be on preventative care
- e. Antibiotics can be an easy treatment plan, but more focus should be on the cause of infection cause
- f. Prescribed multiple medications at once with many side-effects
- g. Some antibiotics are given when unnecessary
- h. Frustrated with diagnosis process and taking antibiotics for a drug resistant infection
- i. Benefits don't outweigh risk
 - i. Do not want to take and/or give them to children
- j. Some patients want to feel better right away without considering risks of medication
- k. Risks of not completing full dose
- l. Concerned because of prevalence of infections are high and antibiotics are over prescribed
- m. Doctors do not ask for patient's opinion
- n. Not enough research exists on the effects of antibiotics
- o. Lack of information provided on medication
- p. Providers too narrowly focused on their specialty
- q. Risk and benefits differ for each individual patient
- r. Large pills with severe side effects for ten days
 - i. Switched medications
 - ii. Suggested to be on medication for two years
 - iii. Still dealing with side effects after taking them
- s. Negative experience on medication
- t. UTI routine diagnosis resulted in lack of care and communication about diagnosis
- u. Felt generalized due to being a Pacific-Islander

3. What do you think overdiagnosis means? What do you think under-diagnosis means?**Over diagnosis:**

- a. Prescribed medication whether needed or not

- b. Minor issue is over emphasized and over treated
- c. Occurs when multiple diagnoses are given
- d. Multiple antibiotics given over several weeks without tests being done, requires own research
- e. Highest dose of medicine given first

Under diagnosis:

- a. Not utilizing use of antibiotics
- b. Provider settling on a routine diagnosis when something more significant is occurring
- c. Convenient to treat and prescribe with antibiotics to be sent home
- d. Not enough concern when treating a routine UTI
- a. In a crisis, not cognizant enough to make a judgment call for yourself
- b. When feeling ok, can wait for results before taking medication
- c. In severe cases, need to take antibiotics right away
- d. Go with what the doctor thinks is best
- e. Diagnosis then treatment is the way to go
- f. Guidelines driven
- g. Situational when it comes to trusting doctor's diagnosis and if to take antibiotics or not

4. How do you know if a hospital is doing a good job?

- a. Hospital ratings would affect decision on where to go for Emergency Medicine*
- b. Hospital ratings does not affect my opinion of hospital*
- c. Don't know what rankings are based on and if the second best is very far behind the top ranking
- d. Ratings for specific specialties beneficial
- e. Reinfection rates are important*
- f. General description of hospital
- g. Diagnosis and care important when choosing a hospital
- h. Care and compassion shown by staff and doctors are highest importance
- i. Want to be treated as an individual
- j. Surveys needed to be done after both negative and positive experiences
- k. Score should exist for rates of prescribing antibiotics
- l. More important to know about diagnosis/misdiagnosis rates than antibiotics prescribed
- m. Most experiences are with providers and not in hospitals necessarily
- n. Too general, how many loose infections are reinfecting people would be better measure
- o. Doctors view themselves as independent from the hospital
- p. Time and money factors into how diagnosis was made

Participant Engagement Session Feedback

- 1. What do you believe are the most important contributions the Virtual Engagement Session will make to the research project?**
 - a. Listening to and not dismissing patients concerns.
 - b. Not over or under prescribing antibiotics
 - c. Recognizing and distinguishing the difference between diagnosis-treatment vs. treatment diagnosis
 - d. Different experiences of the participants provided greater insight
 - e. Breadth and depth of experiences and knowledge*
 - f. Able to provide anecdotal information
 - g. Researchers learned of patient experiences and that it is more important to have a reputable hospital with low rates of reinfection rates than necessarily choosing a specific doctor to seek treatment

- 2. What has made your Virtual Engagement Session participation worthwhile for you personally or for your community?**
 - a. The opportunity to share, learn and support those who work to move medicine forward is always important
 - b. Exposure to the experience of others
 - c. Mainly hearing others' stories
 - d. Hope that the researchers will take what they have learned and use it in the community to make health care better