Title

Evaluating the Amyloidosis Speakers Bureau: The influence of amyloidosis patients' narratives on medical students' knowledge, attitudes, and behavioral intent

Extended data

APPENDIX A: Measures

Questions 1, 2, 4, 5, and 8: Scale: 1 (unlikely) … 7 (likely)
Questions 3, 6 and 7: Scale: 1 (strongly disagree) … 7 (strongly agree)

(*Reverse coded)

Active Communication with Patients
1. I intend to continue to improve my communication skills related to hard-to-diagnose health issues such as amyloidosis.
2. Considering limitations on your time, how likely are you to reevaluate your initial diagnoses when test results or symptoms are inconsistent with them?
3. I recognize that collaborating with other professionals to interpret patients' symptoms may upset patients who rely on my expertise.*

Intent to Acquire & Apply Knowledge of Amyloidosis
4. When observing a constellation of clinical syndromes that do not fit one disease, how likely are you to think of amyloidosis?
5. I intend to take into consideration patients' behaviors, thoughts, and feelings when diagnosing diseases and illnesses.
6. I believe patients' verbally shared symptoms and concerns should sometimes be ignored when diagnosing patients' ailments.*

Willingness to Reconsider Diagnoses
7. I believe that the combined knowledge of the patient and the physician can help provide relevant information about symptoms and aid easier diagnosis.
8. When patients' symptoms are puzzling, I intend to seek further help such as additional tests, referrals, and peer consultations to either confirm or disconfirm my initial diagnoses.

APPENDIX B: Speaker Story Development

Here we offer guidelines to help speakers prepare for a successful presentation.

- **Content:** The key here is to tell <u>your</u> story. From the feedback we have received, what medical students and residents really want to hear about is what has been the speaker's authentic and candid experience with amyloidosis. Think about the important points along the way in your journey. You are the expert when it comes to your story. Do not spend time educating the audience on the disease, as we have other materials and the introductory video from amyloidosis experts to cover that.

- **Develop an outline:** Typically, this will be chronological bullet points from the start of your symptoms to where you are today. You may have key words and phrases with these bullet points, but not full sentences. When delivering, you will periodically refer to your outline while speaking to the audience, but you should not have your head down and read directly from your notes.

  Below we offer aspects of your story which you should consider including. Once you have completed your outline, do a dry run presentation and time yourself. If your time falls short of 30 minutes, add additional detail and personal insights per the questions below; if too long, pare back in non-key areas. Repeat your rehearsal until your time is consistently around 30 minutes.

  - **Getting the disease identified**
    - What was the evolution of symptoms over time?
    - How long did you have symptoms before you decided to see a doctor?
    - What was the sequence and types of doctors you visited?
    - Did you receive mis-diagnoses along the way?
    - Were there missed opportunities for diagnosis along the way?
    - Why did you choose to seek another opinion?
    - How did you know to keep going, keep seeking a diagnosis, and advocating for yourself?

  - **Getting the diagnosis confirmed**
    - What type/specialty of doctor finally correctly identified amyloidosis?
    - What was the definitive diagnosis (both the type and organ involvement)?
    - After how much time and how many doctors was this? Your age at diagnosis?
    - How did you feel when you heard the diagnosis? (Scared? Relieved? Overwhelmed?)

  - **Treatment**
    - What treatments have you had for this disease?
    - Did any of them bring you into remission?
    - What have been the side effects from treatment?
    - Did/Do you participate in any clinical trials? If so, how did you find out about them?
    - What kind of caregiver support did you have during/after treatment?

- **Today and Beyond**
  - What is your disease state today?
  - How has this disease impacted your, and your family's, life?
  - What have been some of the biggest challenges/frustrations you faced?
  - How do you remain hopeful in the face of no cure?
  - With hindsight, is there anything you would/should have done differently?
  - If you have hereditary amyloidosis, and if you are amendable, include comments about your family history, current family (immediate and broader), and genetic testing.
  - Have you been able to subsidize the cost of your medical care and treatment through insurance and government programs?

- **Thoughts for the Medical Community and Future Doctors**
  - What is it like to be your own health advocate?
  - What take-aways would you want doctors to understand from a patient's perspective?