Journal of Cardiac Failure 31 (2025) 492–494

JCF
Journal of Cardiac Failure

An Unexpected Benefit of Adding the Patient Voice to Medical Education—Train Providers to Be Better

Mackenzie N. Boedicker, MS, BS[1] and Deborah D. Boedicker, MBA, BS[1]

ABSTRACT

Background: Amyloidosis is a complex multisystemic disease. Lack of knowledge about amyloidosis and subsequent misdiagnosis or underdiagnosis are major obstacles to treatment that result in life-threatening organ damage, heart failure, morbidity, and mortality. At present, medical didactic education about amyloidosis leaves new physicians woefully unprepared to suspect and diagnose it. A study published in 2023 confirmed a positive impact on medical students following a patient presentation. Continued analysis of the study data revealed an unexpected benefit of adding the patient voice to medical education. The purpose of this paper is to describe this unexpected and potentially powerful benefit.

Methods and Results: The Amyloidosis Speakers Bureau (ASB), founded in 2019, arranges for ASB patient educators to speak about their diagnostic and treatment experiences with medical students. In 2023, we published a study to understand the impact from the addition of the patient voice to didactic medical education. The study concluded that listening to an ASB patient educator's narrative was associated with positive attitudes toward communication with patients, interest in acquiring and applying knowledge of amyloidosis, and humility about diagnosis. Post-publishing, continued analysis of the presentation feedback made it clear that another benefit was occurring. During the ASB presentations, questions were repeatedly raised about what guidance the patients might offer to help these budding doctors become better providers and how they could improve their relationships with patients. Their inquiries had nothing to do with amyloidosis and were relevant to every interaction and all diseases. These future providers wanted to be better and wanted the patient's perspective to help get there. Assessing their questions revealed an unexpected benefit from the patient presentations.

Conclusion: ASB patient educators contributed to humanizing medical education. From this, the students gained insights to help them become better providers. (*J Cardiac Fail 2025;31:492–494*)

Key Words: Heart failure, medical education, amyloidosis, cardiac amyloidosis, patient advocacy, medical curriculum, patient voice, humanizing medical education.

At the Amyloidosis Speakers Bureau, our original goal was to complement and strengthen traditional medical education through the patient voice. We have come to learn that not only are we raising awareness about amyloidosis but there is also a much more significant benefit to our initiative. **We are training providers to be better.**

How We Got Started

We were a trio of two amyloidosis patients and one caregiver who wanted to make an impact in the fight against amyloidosis. At that time, in late 2017, there were no US Food and Drug Administration (FDA)–approved drugs, patient mortality was high, diagnosis rates were low, and

---

From the [1]Amyloidosis Speakers Bureau/Mackenzie's Mission.

Manuscript received September 7, 2024; revised manuscript received November 20, 2024; revised manuscript accepted December 9, 2024.

Reprint requests: Deborah D. Boedicker, Board Member, Mackenzie's Mission. E-mails: MBoedicker16@gmail.com, DBoedicker15@gmail.com

1071-9164/$ - see front matter

https://doi.org/10.1016/j.cardfail.2024.12.007

lives were cut much too short, often by organ failure (heart failure is one of the leading amyloidosis issues). In 2018, the first of a handful of FDA-approved drugs for amyloidosis became available in the United States. With additional FDA-approved drugs becoming available in rapid fashion over the next few years, whether stated in publications,[1,2] at conferences, or in webinars, physicians began stating that lack of awareness about amyloidosis was now one of the biggest issues facing the health care and patient community. This issue resulted in missed or incorrect diagnoses, delayed treatment, and shortened patient lives. It's not that amyloidosis was suddenly more prevalent. With treatments now available, the urgency of getting patients diagnosed increased dramatically. Awareness was too low among practicing clinicians, and patients were now paying the price.

Our group saw this backdrop and felt that we could be part of the solution to educate within the health care community. It was important to us to be distinct from the good work being done by physicians to educate other physicians, whether through conferences, research publications, or networking. We sought to identify gaps in education where we could be impactful and, at the same time, leverage resources we had access to. We discovered a big knowledge gap being built amongst physicians in training and students due to a curriculum that treated amyloidosis as a rare exotic disease that might not be encountered in one's career.

There are some 600 internal medicine residency programs and over 170 medical schools across the United States, developing tens of thousands of future providers with dedicated years of training focused on didactic lectures and clinical rotations. This is a massive pipeline that educates new providers on how to care for patients. We found that the education focused on amyloidosis was overwhelmingly sparse. Perhaps because of the lack of treatments available, or the complexity of being a multisystem disease that might not fit well into typical didactic structures, or maybe because it was deemed so rare, one would never see a patient in the clinic. Regardless, new physicians entering practice were woefully unprepared to diagnose amyloidosis. Yet today, if appropriately diagnosed in a timely manner, the number of amyloidosis patients might tell a very different story. Experts from amyloidosis centers have recognized that it is not as rare as once thought and that medical education today lags behind reality.

To understand why this gap exists, we found two significant challenges facing those providing medical education. First, a vast and ever-growing body of knowledge is needed to educate and train physicians. Amyloidosis is one of approximately 7000 rare diseases regularly squeezed out of inclusion in medical education curricula to focus on the more common diseases (we hear "think horses, not zebras"). When residents and medical students are asked about their knowledge of amyloidosis, the most common answers are either "no knowledge" or "apple green birefringence." Second, multisystem diseases—those whose symptoms regularly affect multiple organs (e.g., heart, nerves, kidney, gastrointestinal tract, liver, etc.)—don't fit neatly into curricula and didactics organized by system blocks. After all, amyloidosis could be discussed in nearly all blocks, capturing one set of symptoms per block, with no place to tie it all together and present a comprehensive view of this disease. While we couldn't change the structure and content of medical didactic education, we remained determined. What could we offer as a complement, yet stand out and be remembered in the minds of trainees and students? Patients. Hearing from live patients is rare during the didactic years, which are loaded with lectures, case studies, grand rounds, and PowerPoint presentations, typically from providers and trainees within the health care community. Yet, patients provide a perspective that these lecturers simply cannot provide—the physical and emotional human journey.

In 2019, we founded the Amyloidosis Speakers Bureau (ASB) as an educational initiative for physicians in training and students developing their knowledge. Speakers Bureaus are generally filled with subject matter experts who are "for hire." We initially considered physicians to be our subject matter experts; however, we quickly understood there would be challenges regarding availability. At the same time, we realized that patients were themselves subject matter experts in their own journey battling amyloidosis. They were interested and available to share their journey as a way to pay it forward and find purpose in the darkness of this disease. Patients were willing to detail their journey from symptoms, diagnosis, treatment, and life today. In addition, they would describe their often unseen emotional battle of fighting this rare, incurable, and life-threatening disease. Patients would be the heart and soul of our medical education initiative and provide a compelling complement to existing didactics. In addition, it was essential to provide an up-to-date clinical perspective to complement live patient narratives, which would be done via prerecorded video. Finally, we would offer our presentations at no cost.

After a couple of years, we sought to answer the question, "Are we making an impact?" We formed a diverse group, developed a questionnaire, and collected and then analyzed the data. The findings? Peer-reviewed research[3] about the ASB confirmed that the impact from the patient narrative was influential and not likely to be forgotten.

The Unexpected Discovery

Continued analysis of our presentation feedback made it clear that another benefit was occurring. During the ASB presentations, questions were repeatedly raised about what guidance the patients might offer to help the budding doctors become better providers and how they could improve their relationships with patients. Their inquiries had nothing to do with amyloidosis and were relevant to every interaction and all diseases. They wanted to be better and wanted the patient's perspective to help get there. We realized that the patient voice and our ASB program had an even bigger benefit—by humanizing education, we could help trainees become better providers. Below, we list broad aspects of feedback that emerged out of the many discussions we have had with trainees and medical experts.

- Listen, listen, listen to your patients.
- Ask about the broader family health.
- Appreciate that the patient may have difficulty explaining what's wrong.
- White coats are intimidating. Sit when talking to patients (vs. standing) and speak with them, not at them.
- Not all patients are confident or skilled at self-advocating.
- Patients often lean on every word a provider says, so choose your words carefully.
- Be honest, and if you can offer any words of hope, do that.
- Assure them you're committed to finding answers.
- Never tell a patient, "It's all in your head." It's insulting.
- Be sure before saying, "There's nothing wrong with you." You just may be wrong.
- When giving a devastating diagnosis, be cognizant of where the patient is when you tell them. Be aware that they might have already seen the diagnosis in their patient portal. Perhaps they should have someone with them (as they may be in a state of shock and not hear everything). Have a next step planned before the conversation ends.
- Emotions may range from fear to relief, change over time, and take time to process. Be there to help in case patients need professional mental health support.

The ASB program raises awareness of amyloidosis in a transformative way that complements traditional didactic medical education. Having completed our fifth academic year, we have presented to over 17,000 current and future health care professionals in over 300 lectures across the United States. Following each lecture, medical students are invited to complete a brief feedback survey. With just over 2000 responses, the data is insightful.

- The medical students were 47.7% first year, 39.9% second year, 9.7% third year, and 2.7% fourth year.
- 42% said they had not learned about amyloidosis in their curriculum.
- 99% found value in the ASB presentation.
- 99.4% learned new information about amyloidosis.
- 44.3% said they would like to periodically receive information about amyloidosis.

Also worth noting, over 3000 ASB medical school attendees will be graduating annually and entering a wide array of specialties—from cardiology to hematology, neurology, nephrology, orthopedics, and many more. The question is, by instilling certain broad perspectives, do we have an opportunity to make physicians better diagnosticians irrespective of a disease state so that rare diseases do not remain rare due to lack of being diagnosed?

Deborah D. Boedicker

Mackenzie N. Boedicker

Conflict of interest statement

Authors have no conflicts of interest to declare.

CRediT authorship contribution statement

Mackenzie N. Boedicker: Writing – review & editing, Conceptualization. **Deborah D. Boedicker:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Acknowledgments

We would like to thank Dr Arvind Bhimaraj for his guidance of this manuscript and thoughtful discussions related to the topic.

References

1. Maurer MS, Bokhari S, Damy T, Dorbala S, Drachman BM, Fontana M, et al. Expert consensus recommendations for the suspicion and diagnosis of transthyretin cardiac amyloidosis. Circ Heart Fail 2019 Sep;12((9):e006075.
2. Gertz MA. Immunoglobulin light chain amyloidosis: 2022 update on diagnosis, prognosis, and treatment. Am J Hematol 2022 Jun 1;97(6):818–29. Epub 2022 Apr 25.
3. Adebayo AL, Rowan KE, Sanchorawala V, Boedicker MN, Boedicker DD. Evaluating the Amyloidosis Speakers Bureau: the influence of amyloidosis patients' narratives on medical students' knowledge, attitudes, and behavioral intent. MedEdPublish (2016) 2023 Jun 28;13:32.