DISCUSSION QUESTIONS

SESSION 1: KNOWLEDGE GAPS IN THE DIAGNOSIS OF CARDIAC AMYLOIDOSIS

Group 1: When to Suspect Cardiac Amyloidosis

Lead moderator: Sanjiv Shah
Group members: Marianna Bruno, Sarah Cuddy, Johana Fajardo, Rebecca Hung, Dipti Itchhaporia, Isabel Lousada, Maria Picken, Bill Seitz, Farooq Sheikh

Discussion Questions:

1. What are the high-yield clinical clues to suggest a diagnosis?

2. What combination of history, medical problems, and exam findings may increase suspicion?
    - Should we focus on a constellation of symptoms rather than an isolated "red flag" to prevent over-testing and over-diagnosis?

3. How can educational efforts be expanded beyond cardiologists and hematologists to better reach internists? What is the role of other specialists, such as orthopedic surgeons and neurologists?

4. Is there a conflict of interest when educational materials are provided by industry sponsors?

5. Can electronic health records assist in decision-support?

Group 2: Common Missteps in the Diagnostic Algorithm

Lead moderator: Martha Grogan
Group members: David Cohen, Angela Dispenzieri, Muriel Finkel, Janell Grazzini Frantz, Jan Griffin, David Hughes, Dan Lenihan, Jaime Murillo, Vaishali Sanchorawala, Katie Zhang

Discussion Questions:

1. What are the sources of false-positives/false-negatives in bone scintigraphy that clinicians need to be aware of?

2. What is the best way to promote best practices, including that monoclonal light chain screen is essential in the interpretation of bone scintigraphy?

3. When is a biopsy necessary to diagnose cardiac amyloidosis, and what should be biopsied?

4. When should an oncologist be involved in the diagnostic process and when is an oncology consultation unnecessary?

5. What ACC tools could provide guidance to increase awareness of cardiac amyloidosis in general, and specifically best diagnostic practices, (e.g., expert consensus pathway, checklist, informational website, phone-based algorithm, one-pager)?

Group 3: Novel Diagnostic Imaging

Lead moderator: Sharmila Dorbala

Group members: Niti Aggarwal, Noel Dasgupta, Preston Dunnmon, Rodney Falk, Mazen Hanna, Jose Nativi-Nicolau, Frederick Ruberg, Brett Sperry, Ron Witteles

Discussion Questions:

1. How can the role of imaging (e.g., echocardiogram, MRI, bone scintigraphy) be refined in terms of diagnosis?
2. What novel imaging techniques may improve diagnostic imaging?
3. What is the optimal multi-modality imaging approach to diagnosis with echocardiogram, MRI, nuclear imaging, and PET?
4. Are there ACC clinical tools that could provide guidance regarding optimal imaging diagnostic strategies (e.g., expert consensus pathway, checklist, informational website, phone-based algorithm, one-pager)?

Group 4: Ramifications of Genetic Testing in Diagnosis and Screening

Lead moderator: Daniel Judge

Group members: Katie Agre, Kevin Alexander, Emily Brown, Kelley Capocelli, Ray Hershberger, Michelle Kittleson, Mary O'Donnell, Ike Okwuosa, Mathew Maurer, Sajiv Shah, Jason Wasfy

Discussion Questions:

1. What are the barriers to clinicians and patients for genetic testing, and how does industry sponsorship affect those barriers?
2. How should the findings of direct-to-consumer genetic testing be managed?
3. Are there scenarios, such as advanced age, where genetic testing should not be included as part of diagnosis?
4. What are the advantages and disadvantages of cascade testing of family members of an affected proband (e.g., uncertainty regarding penetrance, expressivity, and consequences for life and long-term insurance)?
5. How should asymptomatic genetic carriers of TTR mutations be followed?

SESSION 2: UNMET NEEDS IN THE MANAGEMENT OF CARDIAC AMYLOIDOSIS

Group 5: The Role of Active Ascertainment in Cardiac Amyloidosis

Lead moderator: Brett Sperry
Group members: Katie Agre, Emily Brown, Sarah Cuddy, Noel Dasgupta, Sharmila Dorbala, Rodney Falk, Muriel Finkel, David Hughes, Maria Picken, Bill Seitz

Discussion Questions:

1. Should we perform active ascertainment for ATTR-CM and if so, in which populations?
2. What is the cost effectiveness of screening/active ascertainment?
3. Are there biomarkers that can be used for screening purposes?
4. How does bone scintigraphy perform as a screening test?
5. Should TTR gene variants be subject to mandatory reporting?

Group 6: Opportunities for Treatment of Transthyretin Cardiac Amyloidosis

Lead moderator: Mathew Maurer
Group members: Marianna Bruno, David Cohen, Preston Dunnmon, Martha Grogan, Ray Hershberger, Dipti Itchhaporia, Isabel Lousada, Ike Okwuosa, Sanjiv Shah

Discussion Questions:

1. What are the barriers (including financial) to implementation of evidence-based treatment for cardiac amyloidosis?
2. Might the financial incentive for institutions to prescribe tafamidis impact accurate diagnosis?
3. How does one determine whether a patient is progressing on therapy (serial quality-of-life assessments, functional assessments, biomarkers, imaging)?
4. How will stabilizers + silencers + future therapies be incorporated into a treatment algorithm?
5. What is the role of anticoagulation in patients with cardiac amyloidosis without atrial fibrillation?

Group 7: Challenges in Advanced Heart Failure Management

Lead Moderator: Michelle Kittleson
Group members: Angela Dispenzieri, Jan Griffin, Mazen Hanna, Rebecca Hung, Daniel Judge, Jose Nativi-Nicolau, Farooq Sheikh, Ron Witteles

Discussion Questions:

1. What is the role of guideline-directed medical therapy for heart failure with reduced ejection fraction in patients with cardiac amyloidosis?

2. What is the role of defibrillators for primary prevention in patients with cardiac amyloidosis?

3. How do you determine who is sick enough to warrant transplant consideration? What degree of extra-cardiac involvement precludes transplant? What is the role of TTR therapy post transplantation?

4. How do you choose appropriate patients for MCS devices?

5. Is there a role for an ACC clinical tool to promote optimal care for patients with advanced heart failure related to cardiac amyloidosis (e.g., expert consensus pathway, checklist, website or phone-based algorithm)?

Group 8: The Role of Amyloidosis Clinics

Lead Moderator: Frederick Ruberg
Group members: Niti Aggarwal, Kevin Alexander, Kelly Capocelli, Johana Fajardo, Janell Grazzini Frantz, Dan Lenihan, Jaime Murillo, Mary O'Donnell, Vaishali Sanchorawala, Brett Sperry, Jason Wasfy, Katie Zhang

Discussion Questions:

1. What multidisciplinary specialists form the essential components of amyloidosis clinics?

2. Does telehealth offer more barriers or opportunities to facilitate care from specialized centers (e.g., limitations on state licensure)?

3. Should there be recognized minimum criteria for amyloidosis clinics to ensure they can provide optimal care for patients with amyloidosis?

4. Should there be a centralized resource to direct patients to amyloidosis centers (similar to hypertrophic cardiomyopathy or sarcoidosis centers of excellence, or muscular dystrophy clinics with a multidisciplinary focus)?