

## Best Practices in Specialized Amyloidosis Centers in the United States: A Survey of Cardiologists, Nurses, Patients, and Patient Advocates

**Supplemental Table S1.** Amyloidosis center survey methodology and reporting based on COREQ 32-item checklist.<sup>1</sup>

ITEM No.	CHECKLIST QUESTION/DESCRIPTION	SURVEY INFORMATION
<b>DOMAIN 1: RESEARCH TEAM AND REFLEXIVITY</b>		
<i>Personal characteristics</i>		
1. Interviewer	Which author(s) conducted the interview?	Lori Klein
2. Credentials	What were the researcher's credentials? eg, PhD, MD	PharmD
3. Occupation	What was their occupation at the time of the study?	Founder and CEO of Bench Wing, a life sciences consulting firm
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	<ul style="list-style-type: none"> <li>• Experience in life sciences consulting with more than 2 decades of research experience</li> <li>• Post-doctoral fellowship in critical care and infectious diseases research</li> <li>• Collaborated in questionnaire development, received feedback from research team, and conducted all interviews</li> </ul>
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Lori Klein did not have a relationship with any of the participants before conducting the interviews
7. Participant knowledge of the interviewer	What did the participant know about the researcher? eg, personal goals, reasons for doing the research	Participants were informed at the outset of the interviews that the research was being conducted by Bench Wing, a life sciences consulting company, in partnership with Pfizer. In addition, they were told that the goal of the interviews was "to better understand the best practices of amyloidosis centers"

8. Interviewer characteristics	What characteristics were reported about the interviewer?	None
<b>DOMAIN 2: STUDY DESIGN</b>		
<b><i>Theoretical framework</i></b>		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? eg, grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Content analysis was the methodological orientation underpinning the study
<b><i>Participant selection</i></b>		
10. Sampling	How were participants selected? eg, purposive, convenience, consecutive, snowball	<p>Purposive sampling was used</p> <p>Center selection was based on information derived from online research, ie:</p> <ul style="list-style-type: none"> <li>• Years of experience</li> <li>• Number of new amyloidosis patients per year</li> <li>• Center capabilities</li> <li>• Presence of HF program(s)</li> <li>• Number of experts in amyloidosis, ATTR-PN/-CM, and HF</li> <li>• Number of publications on amyloidosis and ATTR-CM</li> <li>• Involvement in amyloidosis and ATTR-CM clinical trials and registries</li> <li>• US News &amp; World Report (2018–2019) ranking as a hospital for cardiology, heart surgery, and HF</li> <li>• Designated amyloid treatment center according to the Amyloidosis Foundation, Amyloidosis Support Groups, My Amyloidosis Pathfinder, National Organization for Rare Disorders, and/or Hypertrophic Cardiomyopathy Association</li> </ul>

Of 17 amyloid centers identified, 2 were excluded because healthcare providers at the centers failed to accept email invitations to participate

11. Method of approach	How were participants approached? eg, face-to-face, telephone, mail, email	Interviews were conducted via telephone (exception: 1 participant provided responses via email)
12. Sample size	How many participants were in the study?	15 cardiologists, 5 nurse practitioners, 4 registered nurses, 16 patients, and 4 patient advocates participated
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Five people refused to participate or dropped out: 1 physician referred his colleague to take his place; 2 nurses were not permitted by their institution to participate; 1 nurse declined participation because of her limited experience at the amyloidosis center; and 1 nurse did not respond to the interviewer after initially agreeing to participate

**Setting**

14. Setting of data collection	Where was the data collected? eg, home, clinic, workplace	Workplace
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16. Description of sample	What are the important characteristics of the sample? eg, demographic data, date	Data was collected from October 2019 to February 2020

**Data collection**

17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot-tested?	Interview guides for healthcare providers, patients, and patient advocates were developed by Lori Klein in consultation with all of her co-authors
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio recorded
20. Field notes	Were field notes made during and/or after the interview?	Yes

21. Duration	What was the duration of the interviews?	1 hour
22. Data saturation	Was data saturation discussed?	Yes. After 16 patient interviews, the researchers decided no further patient recruitment was required
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
<b>DOMAIN 3: ANALYSIS AND FINDINGS</b>		
<b><i>Data analysis</i></b>		
24. Number of data coders	How many data coders coded the data?	1
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	The different questions and their respective answers led to theme identification
27. Software	What software, if applicable, was used to manage the data?	All interviewee responses were recorded and transcribed into Excel spreadsheets, pooling de-identified responses from each type of participant
28. Participant checking	Did participants provide feedback on the findings?	No
<b><i>Reporting</i></b>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? eg, participant number	Feedback was summarized; no direct quotes were attributed to participants
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Minor themes are captured in charts and tables

ATTR-CM, transthyretin amyloid cardiomyopathy; ATTR-PN, transthyretin amyloid polyneuropathy; COREQ, consolidated criteria for reporting qualitative research; HF, heart failure; N/A, not applicable.

**Supplemental Table S2.** Interview guides for amyloidosis center survey of cardiologists, nurses, patients, and patient advocates.

CATEGORY OF SURVEY QUESTIONS	SURVEY QUESTIONS		
	CARDIOLOGISTS	NURSES/NURSE PRACTITIONERS	PATIENTS
Characteristics of the amyloidosis centers, patients, and patients' journey	<ol style="list-style-type: none"> <li>1. How many years has your amyloidosis center been in existence?</li> <li>2. Over the past 12 months, approximately how many amyloidosis patients has your amyloidosis center treated? <ul style="list-style-type: none"> <li>• Newly diagnosed?</li> <li>• What is the % of: <ul style="list-style-type: none"> <li>○ AL vs ATTR amyloidosis?</li> <li>○ ATTRwt vs ATTRv?</li> <li>○ Of those with ATTRv, what % have predominant cardiomyopathy; what % have predominant polyneuropathy?</li> <li>○ Non-TTR, non-AL amyloidosis?</li> </ul> </li> <li>• Has this number changed in the last year? <ul style="list-style-type: none"> <li>○ If yes, why?</li> </ul> </li> </ul> </li> <li>3. Is your amyloidosis center a distinct physical location where patients with amyloidosis exclusively are evaluated or is it part of a larger cardiology or HF clinic or other specialty clinic?</li> <li>4. Does your amyloidosis center have multidisciplinary specialists (eg, cardiology,</li> </ol>	<ol style="list-style-type: none"> <li>1. Please describe your role on the amyloidosis center team.</li> <li>2. Please describe the number and type of staff dedicated to your amyloidosis center including nurses, other non-physician clinical personnel, and non-clinical personnel. <ul style="list-style-type: none"> <li>• What specialties are the non-physician clinical personnel? <ul style="list-style-type: none"> <li>○ Do you have a dedicated physician assistant/NP to support your amyloidosis center?</li> <li>○ Do you have a dedicated RN to support your amyloidosis center?</li> </ul> </li> <li>• What are the roles of the non-clinical personnel?</li> </ul> </li> <li>3. What are your vision and/or aspirations for your amyloidosis center?</li> <li>4. Organizationally, how do you handle the operational issues of managing your amyloidosis center?</li> </ol>	<ol style="list-style-type: none"> <li>1. For how many years have you been receiving care at your amyloidosis center?</li> <li>2. Why did you decide to get treated at an amyloidosis center?</li> <li>3. How did you find your amyloidosis center? <ul style="list-style-type: none"> <li>• Did your physician refer you? If so, what is his/her specialty?</li> <li>• If you found it on your own, how did you become aware of your amyloidosis center?</li> <li>• Did you do any research on your amyloidosis center before you made your decision to get treated there? <ul style="list-style-type: none"> <li>○ If so, where did you look?</li> </ul> </li> </ul> </li> <li>4. What aspect influenced you most in selecting your amyloidosis center (or would if you were selecting it now)?</li> </ol>

	<p>hematology, neurology, gastroenterology) in 1 location to evaluate patients or do patients need to visit different buildings or campuses to see each specialist?</p> <p>5. Please describe the number and type of staff dedicated to your amyloidosis center, including physicians (by type of specialist), non-physician clinical personnel, and non-clinical personnel.</p> <p>6. Are any of the physicians fully dedicated to your amyloidosis center practice?</p> <ul style="list-style-type: none"> <li>• Which physicians play a consultative role vs being fully dedicated?</li> <li>• Are there specific days for seeing patients with amyloidosis or are these appointments interspersed with the other patients you see?</li> </ul> <p>7. Do you have a dedicated physician assistant or nurse practitioner to support your amyloidosis center?</p> <p>8. Do you have a dedicated RN to support your amyloidosis center?</p> <p>9. What are your vision and/or aspirations for your amyloidosis center?</p> <p>10. Organizationally, how do you handle the operational issues of managing your amyloidosis center?</p>	<ul style="list-style-type: none"> <li>• Do you have a clinical operating committee tasked with overseeing the center, handling clinical affairs, ensuring continuous quality improvement, and analyzing the provider base?</li> <li>• Who is responsible for the administrative issues of your amyloidosis center?</li> <li>• Does your amyloidosis center function as an independent unit or do some of these responsibilities fall within a broader organization, eg, the HF or cancer center?</li> </ul>	<p>5. On a scale of 1 to 10, where 10 is really important and 1 is not important at all, how would you rank these other aspects in your decision to select your amyloidosis center:</p> <ul style="list-style-type: none"> <li>• Physician referral</li> <li>• Reputation of the amyloidosis center</li> <li>• Reputation of the hospital/university</li> <li>• Reputation of the ATTR-CM physician</li> <li>• Clinical trials available at the amyloidosis center</li> <li>• Location of the amyloidosis center</li> <li>• Designation as a CoE by another organization, eg, MAP, ASG, AF, or NORD</li> </ul> <p>6. Are there any ways you look for updates from your amyloidosis center?</p>
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	<ul style="list-style-type: none"> <li>• Do you have a clinical operating committee tasked with overseeing the center, handling clinical affairs, ensuring continuous quality improvement, and analyzing the provider base? <ul style="list-style-type: none"> <li>○ If yes, who is on the committee?</li> </ul> </li> <li>• Who is responsible for the financial investment and administrative issues of your amyloidosis center?</li> <li>• Does your amyloidosis center function as an independent unit or do some of these responsibilities fall within a broader organization, eg, the HF or cancer center?</li> </ul>		
<p>Collaboration, coordination, and outreach between amyloidosis centers and community physicians</p>	<p>11. How does your amyloidosis center work with referring physicians?</p> <ul style="list-style-type: none"> <li>• What % of the time do you send patients back to the referring physician after diagnosing ATTR-CM?</li> <li>• In situations where patients don't go back to the referring physicians for management of ATTR-CM, what are the most common reasons?</li> <li>• How do you coordinate care once a patient has been diagnosed with ATTR-CM?</li> </ul>	<p>5. How do you coordinate care with the referring physician office once a patient has been diagnosed with ATTR-CM?</p> <ul style="list-style-type: none"> <li>• If they receive care from a local HF clinic, do you coordinate in some way with the local HF nurse?</li> <li>• When you are coordinating care with a referring physician, who writes prescriptions or orders lab tests and imaging for their ATTR-CM management?</li> </ul>	<p>7. Do you receive all your care for ATTR-CM at your amyloidosis center or do you still see the cardiologist (or referring physician) you had before you registered at the amyloidosis center?</p> <ul style="list-style-type: none"> <li>• In a year, how often do you have appointments with your amyloidosis center vs your local cardiologist?</li> </ul>

	<ul style="list-style-type: none"> <li>• Do you have any care pathways to guide outside providers on the coordination of care?</li> </ul> <p>12. Can you describe your perception of the typical referral patterns for patients with ATTR-CM?</p> <ul style="list-style-type: none"> <li>• Where do your patients come from?</li> <li>• Which specialties most commonly refer patients?</li> <li>• What % come from within your organization vs external?</li> <li>• What % are local, regional, national, or international? (The answer for the 4 options should total 100%.)</li> <li>• What % of patients referred with suspected cardiac amyloidosis do you confirm have cardiac amyloidosis?</li> </ul> <p>13. Do you receive patients as a result of your designation as an amyloidosis center from other organizations, eg, MAP, ASG, AF, or NORD?</p> <ul style="list-style-type: none"> <li>• What do these types of endorsements mean to your organization?</li> <li>• Are they something your amyloidosis center strives to achieve?</li> </ul> <p>14. What does your institution do to increase awareness of the expertise of your amyloidosis center among physicians and patients?</p>	<ul style="list-style-type: none"> <li>• Do you provide any education to the referring physician team about managing ATTR-CM?</li> <li>• Do you typically know the details of the patient's journey to a diagnosis before they were referred to your amyloidosis center? <ul style="list-style-type: none"> <li>○ If so, do you know this information from the patient or the referring physician?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Who writes your prescriptions for ATTR-CM? Where do you have those prescriptions filled?</li> <li>• Who orders lab tests or imaging tests for ATTR-CM? Where do you have those tests completed?</li> <li>• If your care is coordinated between your amyloidosis center and your local physician, do you find any difficulties or challenges with this arrangement?</li> </ul> <p>8. Do you ever use videoconferencing to have follow-up conversations with your amyloidosis center physicians?</p> <p>9. Do any of your amyloidosis center physicians ever make visits to a local clinic or hospital to see you?</p> <p>10. Does your amyloidosis center have a healthcare support portal to communicate with you?</p>
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<p>Best practices and ideal features of the amyloidosis centers</p>	<p>15. What are a couple of the best practices within your amyloidosis center?</p> <p>16. Are there efficiencies and/or cost savings afforded by your amyloidosis center?</p> <p>17. What are some of the challenges for your amyloidosis center?</p> <p>18. If you were giving advice to someone setting up a new amyloidosis center, are there things to avoid or mistakes you have learned from in running your amyloidosis center?</p> <p>19. What metrics do you use to measure the success of your amyloidosis center?</p>	<p>6. What are a couple of the best practices within your amyloidosis center?</p> <ul style="list-style-type: none"> <li>• Is there a nurse-specific example?</li> </ul> <p>7. Are there efficiencies and/or cost savings afforded by your amyloidosis center?</p> <p>8. What are some of the challenges for your amyloidosis center?</p> <p>9. What metrics do you use to measure the success of your amyloidosis center?</p> <p>10. How does your amyloidosis center team continue to advance its knowledge and training in cardiac amyloidosis?</p>	<p>11. What do you think your amyloidosis center does really well?</p> <p>12. Does your amyloidosis center conduct patient satisfaction surveys?</p> <p>13. In your opinion, what would make an ideal amyloidosis center?</p>
<p>Diagnostic approaches followed at amyloidosis centers</p>	<p>20. What % of new patients you receive with ATTR-CM already have a diagnosis?</p> <ul style="list-style-type: none"> <li>• How far along the diagnostic work-up have most referred patients gotten?</li> <li>• Are there aspects of the diagnostic work-up that may have been done by the referring physician that you repeat to confirm the diagnosis?</li> <li>• Do you routinely use strain imaging as part of your echo evaluation of amyloid patients?</li> </ul> <p>21. What % of your patients with ATTR-CM are diagnosed by your institution's HF program?</p>	<p>11. How do you ensure the patient understands ATTR-CM after they have been diagnosed?</p> <p>12. Who spends the time to educate the patient?</p> <p>13. Do you include the family and/or caregiver in the patient's education?</p> <p>14. What information gets covered in a patient's education for ATTR-CM?</p> <p>15. Approximately how much time does your amyloidosis center spend educating patients on ATTR-CM?</p> <ul style="list-style-type: none"> <li>• Do you feel it is enough?</li> </ul> <p>16. Do you ever have follow-up calls with the patient when they are at home to discuss</p>	<p>14. Did you receive your diagnosis of ATTR-CM at your amyloidosis center?</p> <ul style="list-style-type: none"> <li>• How many years ago were you diagnosed?</li> </ul> <p>15. Did you have a cardiac biopsy and/or PYP scan?</p> <p>16. Did you receive genetic testing for your amyloidosis?</p> <ul style="list-style-type: none"> <li>• Did you talk to a genetic counselor?</li> <li>• Was your family included in this discussion?</li> </ul>

	<p>22. In your amyloidosis center, who is involved in the typical diagnostic work-up for a patient with ATTR-CM?</p> <p>23. What % of the time do you use the following in diagnosing patients with ATTR-CM:</p> <ul style="list-style-type: none"> <li>• PYP scintigraphy</li> <li>• Endomyocardial biopsy</li> <li>• Genetic testing</li> </ul> <p>24. Do you ever use PYP scintigraphy in patients with suspected AL amyloidosis?</p> <p>25. What % of PYP-positive patients have an abnormal monoclonal protein on serum/urine testing?</p> <p>26. If a patient with ATTRv presents with significant neuropathy and no HF, do you routinely evaluate for the presence of cardiac involvement and/or do your neurologists routinely refer to you for a cardiac assessment?</p> <p>27. Do you ascribe to a particular diagnostic algorithm?</p> <p>28. What is the duration of the initial visit with you for a new patient with amyloidosis?</p> <p>29. Do you incorporate genetic counselors in the management of your patients?</p>	<p>questions they may have or provide additional training?</p> <p>17. Do you meet more than once to educate a patient on ATTR-CM?</p> <p>18. Do you provide any printed materials or online resources?</p> <ul style="list-style-type: none"> <li>• What does the material cover?</li> <li>• Where do you get educational materials?</li> <li>• How do you ensure they stay updated?</li> <li>• Are there any items you wish you had for educating patients about ATTR-CM?</li> </ul> <p>19. When you are educating patients about ATTR-CM, what works well?</p> <ul style="list-style-type: none"> <li>• What doesn't work?</li> </ul> <p>20. Do you offer patient education seminars, advocacy meetings, support groups, or similar programs within your amyloidosis center?</p>	<ul style="list-style-type: none"> <li>• What were the key concerns you wanted addressed?</li> </ul>
		<p>21. Do you have any systems in place to screen "hot spots" for patients who may have ATTR-CM?</p>	

	<ul style="list-style-type: none"> <li>• How do you discuss genetic testing implications with the family?</li> <li>• If a family member is found to have a <i>TTR</i> mutation but is asymptomatic, do you have any type of surveillance program to monitor them?</li> </ul> <p>30. Do you have any systems in place to screen “hot spots” for patients who may have ATTR-CM?</p>		
<p>Amyloidosis center approaches to multidisciplinary care</p>	<p>31. Do the different specialties see patients together?</p> <ul style="list-style-type: none"> <li>• Do you have any multidisciplinary review meetings to discuss an individual patient?</li> <li>• Do you have a dedicated amyloidosis clinic day? How frequently do you meet?</li> </ul> <p>32. How do you work with your specialty pharmacy?</p> <ul style="list-style-type: none"> <li>• Do you have one within your health system?</li> <li>• Which ATTR amyloidosis drugs do they help you with?</li> <li>• What are some of the positive aspects of working with your specialty pharmacy?</li> <li>• Are there any challenges working with your specialty pharmacy?</li> </ul>	<p>22. How many physicians or other members of the team does a patient see in a follow-up visit to your amyloidosis center?</p> <ul style="list-style-type: none"> <li>• Who would they typically be?</li> <li>• Who coordinates appointments with all the specialists the patient needs to see on a visit?</li> </ul> <p>23. Do the different specialties ever see patients together?</p> <ul style="list-style-type: none"> <li>• Do you have any multidisciplinary review meetings to discuss an individual patient? <ul style="list-style-type: none"> <li>○ If yes, who is included?</li> </ul> </li> <li>• If your specialists do meet together, is this primarily done for diagnosis and/or treatment or do you have meetings to discuss follow-up patient appointments?</li> </ul>	<p>17. How many physicians and other personnel do you usually see when you visit your amyloidosis center?</p> <ul style="list-style-type: none"> <li>• Could you share what expertise they have, eg, what type of specialists, nurses, patient navigators?</li> <li>• What is your perspective on seeing multiple specialists at your amyloidosis center?</li> </ul> <p>18. Does your amyloidosis center have multidisciplinary specialists (eg, cardiology, hematology, neurology, gastroenterology) in 1 location to evaluate patients or do patients need to visit different buildings or campuses to see each specialist?</p>

		<p>24. If a patient calls with questions or concerns between their appointments at the amyloidosis center, who do they usually speak with?</p> <ul style="list-style-type: none"> <li>• Do they have a specific person to call?</li> <li>• Do you have a healthcare support portal for your patients to facilitate communication around test results, prescription refills, or appointment reminders?</li> </ul> <p>25. Do you have a patient concierge service and/or patient navigators?</p> <ul style="list-style-type: none"> <li>• What role do they play?</li> </ul> <p>26. How do you work with your specialty pharmacy?</p> <ul style="list-style-type: none"> <li>• Do you have one within your health system?</li> <li>• Which ATTR amyloidosis drugs do they help you with?</li> <li>• What are some of the positive aspects of working with your specialty pharmacy?</li> <li>• Are there any challenges working with your specialty pharmacy?</li> </ul> <p>27. Do you have any palliative care specialists who partner with you in caring for patients with ATTR-CM?</p>	<p>19. Do you have a dedicated point person or a patient navigator at the amyloidosis center who helps you with all your appointments and tests?</p>
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<p>Barriers to patient access to amyloidosis centers</p>		<p>28. What are the common issues that negatively impact the QoL of patients with ATTR-CM (can be health-related or not health-related)?</p> <ul style="list-style-type: none"> <li>• Do you have any examples of how your amyloidosis center addresses these issues?</li> </ul> <p>29. What type of patient support does your amyloidosis center provide to address barriers to accessing care?</p> <p>30. Are there any other staff or services you have in place to improve the experience of your patients?</p>	<p>20. Are there any challenges you face in getting treatment at your amyloidosis center?</p> <p>21. How far away is your amyloidosis center from your home (travel time in minutes)?</p> <p>22. When you go to the amyloidosis center, how long are you usually there?</p> <p>23. How do you travel to the amyloidosis center?</p> <ul style="list-style-type: none"> <li>• Does anyone go with you?</li> <li>• Do you ever have to stay overnight?</li> </ul> <p>24. What is the most difficult thing about having ATTR-CM?</p> <ul style="list-style-type: none"> <li>• Is there anything your amyloidosis center has done to make that situation easier?</li> </ul>
<p>Role of clinical research and registries</p>	<p>33. Approximately what % of your patients are enrolled in a clinical trial?</p> <ul style="list-style-type: none"> <li>• Approximately what % of your patients are enrolled in a registry?</li> </ul> <p>34. Do you keep an institutional registry of patients with cardiac amyloidosis?</p>	<p>31. How and when are patients enrolled in a clinical trial and/or registry?</p> <ul style="list-style-type: none"> <li>• Who is involved in discussing a potential clinical trial and/or registry with the patient?</li> <li>• If the patient decides to participate, who is involved in getting them enrolled?</li> </ul>	<p>25. Does your amyloidosis center make you aware of clinical trials or registries that are available to you?</p> <p>26. Have you participated in any clinical trials or registries for ATTR-CM?</p> <ul style="list-style-type: none"> <li>• Why/why not?</li> </ul>

	<p>35. To what extent does the availability of a clinical trial and/or registry play a role in patients seeking your amyloidosis center?</p> <p>36. What % of your amyloidosis center is dedicated to research vs clinical care?</p>	<ul style="list-style-type: none"> <li>• If they don't initially want to participate in a clinical trial and/or registry, do you ever follow up to let them know about new opportunities?</li> </ul> <p>32. To what extent does the availability of a clinical trial and/or registry play a role in patients seeking your amyloidosis center?</p>	<p>27. Does your amyloidosis center send you information on new research findings?</p> <p>28. Does your amyloidosis center keep you informed of new clinical trial opportunities?</p>
<p>Collaboration between amyloidosis centers and patient support organizations</p>	<p>37. In what ways do you partner with patient organizations such as ASG, AF, or ARC?</p>	<p>33. Do you introduce your patients with ATTR-CM to any patient organizations?</p> <ul style="list-style-type: none"> <li>• Which ones?</li> <li>• How do you make the introduction?</li> </ul> <p>34. In what ways do you partner with patient organizations like ASG, AF, or ARC?</p> <ul style="list-style-type: none"> <li>• Can you give an example of how you work with each organization?</li> </ul> <p>35. Do any of the patient organizations visit your center?</p> <ul style="list-style-type: none"> <li>• What is the purpose of their visit?</li> </ul> <p>36. Do you provide patients with educational materials that were developed by ASG, AF, or ARC?</p> <p>37. Do you make patients aware of upcoming seminars, conferences, or meetings sponsored by ASG, AF, or ARC?</p>	<p>29. Did your amyloidosis center tell you about any amyloidosis patient organizations, eg, AF, ASG, or ARC?</p> <p>30. Does your amyloidosis center host any amyloidosis patient support meetings or events in collaboration with AF, ASG, or ARC?</p> <p>31. Does your amyloidosis center provide educational materials to you that were developed by AF, ASG, or ARC?</p> <p>32. Does your amyloidosis center make you aware of upcoming seminars, conferences, or meetings sponsored by AF, ASG, or ARC?</p>

		38. Are there any ways you connect or collaborate with other amyloidosis programs?	
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**SURVEY QUESTIONS**

**PATIENT ADVOCATES FROM PATIENT SUPPORT GROUPS**

1. What are the typical ways you work with amyloidosis centers in the US?
2. Do patients reach out to you for recommendations on where to seek care for their amyloidosis? If so, what factors do you consider when recommending a center?
3. What factor influences you most in recommending an amyloidosis center?
4. On a scale of 1 to 10, where 10 is really important and 1 is not important at all, how would you rank these factors in the selection of an amyloidosis center in the US for a patient with known or suspected ATTR-CM:
  - Reputation of the amyloidosis center, eg, established vs new centers
  - Reputation of the hospital/university
  - Reputation of the ATTR-CM physician, eg, publications, presentations at International Society of Amyloidosis meetings, grand rounds, amyloidosis patient seminars, sponsorship of their own amyloidosis conferences
  - Company-sponsored clinical trials available at the amyloidosis center
  - Participation in national registries
  - Physician conducting independent research on amyloidosis
  - Presence of a strong HF program
  - Availability of support groups or educational seminars at the amyloidosis center
  - Location of the amyloidosis center
  - Multidisciplinary care team

7. In your opinion, what makes an ideal amyloidosis center?
8. Are there any best practices that amyloidosis centers follow outside of the US that would be valuable to consider in the US?
9. Are there things you do to support newly created amyloidosis centers? Do you do anything to help existing amyloidosis centers improve?
10. What are some opportunities to increase the likelihood of patients finding an amyloidosis center earlier in their journey to receive a diagnosis?
11. What is your perspective on how to raise awareness of amyloidosis centers among referring physicians?
12. What are some effective things you see amyloidosis centers doing to raise awareness of their expertise?
13. What are the common challenges patients face in getting diagnosed at an amyloidosis center?
14. What are the common challenges patients face in accessing treatment at an amyloidosis center?
15. Aside from the information on your website, are there other ways that you support amyloidosis centers?
16. How do patients usually find your organization?
17. Based on our conversation, is there anything else you feel should be considered about best practices in amyloidosis centers?

<ul style="list-style-type: none"> <li>• Physician multidisciplinary team treats patients in a distinct physical location</li> <li>• Availability of patient (nurse) coordinators</li> <li>• Well-coordinated center, eg, seamless appointment scheduling, multidisciplinary team sees patient same day</li> <li>• Years of experience treating amyloidosis</li> <li>• Number of amyloidosis patients treated per year</li> <li>• Length of time spent evaluating patients for initial diagnosis, education, and ongoing appointments</li> <li>• Direct availability of physician and/or dedicated nurse for patient questions, eg, phone, email, text</li> </ul> <p>5. Do you routinely recommend that patients get treated at an established amyloidosis center:</p> <ul style="list-style-type: none"> <li>• To confirm the diagnosis?</li> <li>• For all care?</li> </ul> <p>6. How do you determine the amyloidosis centers that are listed on your website?</p> <ul style="list-style-type: none"> <li>• What criteria do you consider if you list as a CoE?</li> <li>• What should a newer amyloidosis center do to be considered?</li> </ul>	
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AF, Amyloidosis Foundation; AL amyloidosis, light-chain amyloidosis; ARC, Amyloidosis Research Consortium; ASG, Amyloidosis Support Groups; ATTR amyloidosis, transthyretin amyloidosis; ATTR-CM, transthyretin amyloid cardiomyopathy; ATTRv, variant transthyretin amyloidosis; ATTRw, wild-type transthyretin amyloidosis; CoE, center of excellence; echo, echocardiogram; HF, heart failure; MAP, My Amyloidosis Pathfinder; NORD, National Organization for Rare Diseases; NP, nurse practitioner; PYP, <sup>99m</sup>technetium-pyrophosphate; QoL, quality of life; RN, registered nurse; TTR, transthyretin.

## REFERENCE

1. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349-357.