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Developing, optimizing, and evaluating patient infographics for diagnosing cardiac amyloidosis

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ABSTRACT

Objective: Advancements in diagnostics and treatment options for cardiac amyloidosis have improved patient outcomes, yet few patient education materials exist to help patients understand the disease and diagnosis process. We sought to develop and evaluate a set of plain language, patient-centered infographics describing the condition and common diagnostic tests.
Methods: Using health literacy best practices, we developed 7 infographics which were further revised based on multilevel stakeholder feedback. To evaluate the materials, we recruited 100 patients from healthcare settings in Chicago, IL; participants completed a web-assisted interview during which they were randomized 1:1 to first view either our infographics or a standard material. Participants completed a knowledge assessment on their assigned material and subsequently reported impressions of both materials.
Results: No differences were found between study arms in knowledge. The infographics took significantly less time to read and were more highly rated by participants in terms of appearance and understandability. Over two-thirds of participants preferred the infographics to the standard.
Conclusions: The infographics created may improve the learning process about a complex condition and diagnosis process unknown to most adults.
Innovation: These infographics are the first of their kind for cardiac amyloidosis and were created using health literacy best practices.

1. Introduction

Cardiac amyloidosis is a serious and progressive disease that occurs when misfolded amyloid proteins accumulate in heart tissue. The most common types of amyloid proteins that are deposited in heart include light chain (AL) and transthyretin (ATTR-CM) [1]. Their presence can cause disruption of normal cardiac and electrical function and make it increasingly difficult for the heart to efficiently pump blood,; in turn, this can lead to heart failure and reduced quality of life [2]. Making the diagnosis of cardiac amyloidosis can be challenging in part because the signs and symptoms of heart failure are similar regardless of the etiology. They include: fatigue; difficulty breathing; swelling in the ankles, legs, or stomach; feeling dizzy; and pressure in the chest.

Although cardiac amyloidosis does not yet have a cure, recent

Abbreviations: AL, light chain amyloid in the heart; ATTR-CM, transthyretin amyloid in the heart.

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advancements in diagnostics and treatment options have led to improved patient outcomes, particularly when diagnosis occurs early in the course of the disease [3]. Nevertheless, when clinicians suspect a patient may have cardiac amyloidosis, patients must undergo a series of diagnostic tests to determine whether they have the condition, and if so, to identify the type of amyloid; results of these tests are necessary to drive appropriate treatment decisions [4].

While cardiac amyloidosis has long been considered a rare disease, recent evidence suggests it is likely underdiagnosed [3,5-9]. Efforts to increase clinician awareness of the disease are therefore underway [10]. However, patients should also be made aware. A large body of research has revealed that patient education can positively impact health behavior and health outcomes; those who are more informed about their health are more likely to be engaged and follow through with diagnosis and treatment plans [11-15]. Nevertheless, other than websites pertaining to select medical organizations, few educational materials exist to provide patients with a comprehensive understanding of cardiac amyloidosis and the necessary, multistep diagnostic process [16,17].

In this study, we sought to develop a set of patient-friendly infographics explaining cardiac amyloidosis, as well as the process and tests through which the disease is typically diagnosed. We also sought to evaluate whether patients who viewed our infographics versus a standard material, comprised of content from publicly available websites, would exhibit greater knowledge of cardiac amyloidosis and the related diagnostic tests and procedures. The availability of such a set of infographics would fill a gap in current patient education resources and could be beneficial to aid patient-provider communication on this condition, potentially leading to more informed physician-patient consultation and patient engagement.

2. Methods

2.1. Ethical approval

All study procedures were approved by the Northwestern University Institutional Review Board (IRB). Material development activities were creative and not considered human subjects research. Nevertheless, patient participants in both the material development activities and the evaluation provided informed verbal consent prior to participation and were compensated for their time.

2.2. Phase 1: material development

The first step in this study was to create content in plain language that could both educate patients about cardiac amyloidosis and describe the diagnostic tests commonly utilized for diagnosis. This process comprised a review of the literature, the development of initial draft infographics, cognitive interviews and optimization of the infographics, and selection of the standard material for eventual comparison.

2.3. Review of the literature

We began by reviewing the scientific literature and consulting clinical guidelines to identify publicly available cardiac amyloidosis education materials for patients; this included a search of published research using the PubMed search engine, as well as a search of websites pertaining to leading health organizations (i.e., The American Heart Association). Results revealed no publicly available materials designed specifically about cardiac amyloidosis for patients.

2.4. Development of initial draft infographics

To address this gap, we drafted text explaining cardiac amyloidosis and the multistep diagnosis process. With the help of a graphic designer, we then transformed the text into a set of infographics that used color and graphics to convey pertinent information. The infographics also incorporated health literacy 'best practices' to enhance readability and understandability [18-21]. Specifically, we used plain language, short sections of text, and incorporated images to support learning. In total, the infographics comprised seven pages that could be viewed individually or together. The infographics described: 1) cardiac amyloidosis, 2) steps taken to diagnose cardiac amyloidosis, 3) electrocardiography, 4) echocardiography, 5) magnetic resonance imaging (MRI), 6) blood and urine tests, and 7) scintigraphy.

Initial drafts of the infographics were then shown to two cardiologists who have experience diagnosing and providing care to patients with cardiac amyloidosis; they were also shown to a cardiac amyloidosis patient advocacy group. Multiple rounds of consultations with the graphic designer, cardiologists, the advocacy group, and our study team resulted in a final set of draft infographics deemed to be scientifically accurate and potentially appropriate for a lay audience.

2.5. Cognitive interviews and infographic optimization

Using convenience sampling from community and online settings (i.e., Craigslist), we then identified lay advisors without a diagnosis of cardiac amyloidosis. These advisors were selected to participate in cognitive interviews in which they reviewed the materials and provided an indication as to whether individuals without prior disease-related knowledge could navigate and understand the infographics. Five racially diverse, older (age $\geq$ 50 years), English-speaking lay advisors participated in individual, hour-long discussions held remotely via secure web-conferencing technology. The number and format of these cognitive interviews were informed by previously established guidelines for cognitive interviews [22]. During the interviews, lay advisors were asked to review the infographic pages and to provide structured feedback on the appearance and content. To ensure sufficient review time was allotted to each infographic page, the page order varied by lay advisor. Participant suggestions were summarized; those that enhanced the readability and understandability of the material were incorporated for a final review by the cardiologists and study team. The end result was an optimized set of the infographics for evaluation (See Supplementary Materials).

2.6. Selection of the standard material

For the standard material, we utilized a publicly available, 12-page patient education tool from a leading medical organization. The tool provided a comprehensive review of amyloidosis. As such, we removed three pages that described amyloidosis in other organ systems, as they were not specific to cardiac amyloidosis. The standard material we used in the evaluation, therefore, totaled nine pages and provided detailed information, written in large font, on cardiac amyloidosis, MRI, and echocardiography.

2.7. Phase 2: Randomized experiment

We then evaluated the infographics in a two-arm, cross-sectional randomized experiment among patients receiving care from academic and community health settings in metropolitan Chicago, IL.

2.8. Participant eligibility and recruitment

Eligibility criteria for the randomized experiment was purposefully broad as we intended to recruit individuals who have not yet experienced cardiac health concerns. Eligibility included being aged 50 to 80, as cardiac amyloidosis is more likely to affect this age group. It also included being English-speaking, having access to the internet, and having an active email address; these criteria were necessary to conduct the remote interviews. Individuals were excluded from participating if they had previously spoken with a healthcare provider about cardiac amyloidosis, had ever had an MRI or echocardiogram, or had any severe,

uncorrectable hearing, vision or cognitive impairment that would preclude study consent or participation.

From April to June 2022, individuals potentially eligible to participate were identified via electronic health record (EHR) data queries at Northwestern Medicine and through prior participation in research studies conducted by our team at local community health centers. Potentially eligible participants were sent a letter briefly describing the study and providing an opportunity to opt-out of being contacted by a research assistant (RA). Those who did not opt out were called by an RA who introduced the study, and screened patients for eligibility. Those eligible and interested were subsequently engaged in the informed verbal consent process and enrolled in the study.

2.9. Randomization and data collection

Study participants were mailed a package that contained two sealed envelopes. One envelope (marked A) contained our newly created infographics. The other envelope (marked B) contained standard patient education material from a leading medical organization. At the beginning of the interview, participants were randomized 1:1 with random permuted block sizes of four using PROC PLAN in SAS (Cary, NC). Participants were randomized to view either the infographics or the standard material first. Participants were then asked to open their assigned envelope over a secure videoconferencing platform while the RA watched. Participants read their assigned material in depth; the amount of time taken to read the document was recorded by the RA. Using only their assigned material as a reference, participants subsequently completed a brief 'open book' knowledge questionnaire and answered a series of questions related to their impressions of the material. Participants were then asked to open the other sealed envelope and to read the alternate material. The amount of time taken to read this material was again recorded by the RA. After viewing the alternate material, participants were asked the same set of questions about their impressions of the material, as well as which one they preferred. Finally, participants were asked to answer questions regarding their sociodemographic and health characteristics.

2.10. Study measures

For this study, knowledge was the primary outcome. It was measured using a 12 item, structured questionnaire designed by our team to assess understanding of cardiac amyloidosis and two specific diagnostic tests: cardiac MRI and echocardiogram (See Supplementary Materials). The knowledge assessment was 'open book'; as such, participants were encouraged to look at their assigned material while answering each question. Applying methods from previous studies, our team created the knowledge assessment using questions that could be correctly answered when viewing either the infographics or the standard patient education material [20,23]. In total, the assessment comprised eight items with multiple-choice responses options and four with True/False response options. To analyze knowledge scores, we calculated both a percentage of correct responses and a binary outcome measure. The binary measure was set with an a priori threshold of 85%, corresponding to the FDA's target comprehension goal [24]. Participants were deemed knowledgeable about the information provided if they correctly answered $\geq$85% of the items.

Participants' experiences with and impressions of the materials were considered secondary outcomes. Unlike for the primary outcome, participants were asked these questions of both materials, first of their randomly assigned material, and subsequently of the other. Specifically, secondary outcomes included the RA's documentation of the time it took each participant to read the materials. Secondary outcomes also included participants' perceptions of the appearance and quality of the materials; each of these questions were measured on a 5-point Likert scale (poor to excellent). Participants were further asked how easy the materials were to read and understand, and how likely they would be to read the materials if provided to them by a doctor; these questions were each measured using 10-point scales (not easy to very easy; not likely to very likely, respectively). Finally, participants were asked to indicate which material they preferred.

After discussing the materials, participants provided sociodemographic information (e.g., age, sex, education, income, race, and ethnicity) and health characteristics (e.g., health status, health conditions). They also completed the Newest Vital Sign (NVS), a validated measure of health literacy which patients to interpret information provided on a nutrition label [25]. This nutrition label was mailed to participants along with the other study materials.

2.11. Analyses

Analyses for this study were conducted using SAS (Cary, NC). Participants' sociodemographic and health characteristics were examined using descriptive statistics. Health literacy was assessed using published criteria for the NVS, classifying participants as having either adequate or limited (low/marginal) literacy skills [25]. Participant knowledge and impressions of the reviewed material were examined using bivariate analyses. For these analyses, $\chi 2$, *t*-tests or ANOVA were employed as appropriate by study arm, and subsequently, across sociodemographic characteristics. For the primary outcome of knowledge, multivariable linear analyses were conducted to assess whether participants viewing the infographics achieved higher total knowledge scores than those viewing the standard material, after accounting for participants' income, sex, and health literacy. Similar logistic analyses were conducted to examine whether participants viewing the infographics were more likely to achieve the $\geq$85% comprehension compared to those viewing the standard material.

3. Results

3.1. Participant characteristics

Table 1 provides an overview of participants' characteristics, including characteristics by study arm. In total, we enrolled 100 participants ($n = 70$ from Northwestern Medicine and $n = 30$ from prior studies conducted at community health centers). Nearly two thirds of participants in our sample were women (61.00%). The average age of participants was 62.41 years old (SD = 7.47), about half were non-Hispanic White (53.00%), and a quarter were non-Hispanic Black (25.00%). A slight majority (58.00%) had a college education or more, and 32.00% had limited health literacy. Most participants self-reported 'very good' or 'excellent' health (55.00%). There were no significant differences in participant socio-demographics by study arm.

3.2. Primary outcome: knowledge

Bivariate analyses revealed no significant differences in total knowledge score by study arm; on average, participants in both arms answered approximately 10 out of 12 items correctly. Furthermore, while participants assigned to the infographics were more likely to reach the 85% knowledge threshold than those assigned to the standard patient education material, this difference was not statistically significant (48.00% vs. 38.00%, $p = .31$; Table 2).

Multivariate analyses controlling for income, sex, health literacy and age, similarly revealed no significant differences in total knowledge score by study arm ($p = .18$). However, participants assigned to the infographics remained more likely to reach the 85% knowledge threshold than those assigned to the standard material; this difference approached statistical significance ($p = .06$; Table 3).

Table 1
Characteristics of study sample; overall and by randomized 1st patient document exposure.

Characteristic	Overall sample (N = 100)	1st Patient document exposure		P-value
		Infographics (n = 50)	Standard (n = 50)	
Age, Mean (SD), years	62.41 (7.47)	62.62 (7.36)	62.20 (7.65)	0.79
Sex, n (%)				0.84
Male	39 (39.00)	19 (38.00)	20 (40.00)	
Female	61 (61.00)	31 (62.00)	30 (60.00)	
Race and Ethnicity, n (%)				0.44
Hispanic/Latino	20 (20.00)	11 (22.00)	9 (18.00)	
Non-Hispanic Black	25 (25.00)	14 (28.00)	11 (22.00)	
Non-Hispanic White	53 (53.00)	25 (50.00)	28 (56.00)	
Asian	2 (2.00)	0 (0.00)	2 (4.00)	
Educational Attainment, n (%)				0.39
High School Graduate or less	17 (17.00)	11 (22.00)	6 (12.00)	
Some College/ Technical School	25 (25.00)	11 (22.00)	14 (28.00)	
College Graduate or Higher	58 (58.00)	28 (56.00)	30 (60.00)	
Health Literacy, n (%)				0.67
Limited	32 (32.00)	17 (34.00)	15 (30.00)	
Adequate	68 (68.00)	33 (66.00)	35 (70.00)	
Household Income[a], n (%)				0.27
< $25,000	24 (24.74)	16 (32.65)	8 (16.67)	
$25,000 - $99,999	29 (29.90)	14 (28.57)	15 (31.25)	
$100,000–$199,999	30 (30.93)	12 (24.49)	18 (37.50)	
≥ $200,000	14 (14.43)	7 (14.29)	7 (14.58)	
Very good/excellent health, n (%)	55 (55.00)	24 (48.00)	31 (62.00)	0.16

[a] 3 missing.

Table 2
Knowledge, overall and by 1st randomized patient document exposure.

Outcome	Overall sample (N = 100)	1st Patient document exposure		P-value
		Infographics (n = 50)	Standard (n = 50)	
Total Knowledge Score (0–12), M (SD)	9.90 (1.47)	9.96 (1.62)	9.84 (1.33)	0.69
≥ 85% correct responses, n (%)	43 (43.00)	24 (48.00)	19 (38.00)	0.31

Table 3
Multivariable analysis of participant knowledge.

Variable	Study arm		P-value
	Standard material	Infographics	
	Odds ratio (95% CI)	Odds ratio (95% CI)	
Total knowledge score	Ref	0.26 (−0.16–0.86)	0.18
≥ 85% Correct Responses	Ref	2.88 (0.97–8.57)	0.06

3.3. Secondary outcomes: participant experiences with and impressions of study materials

Overall, there were significant differences in the amount of time it took participants to read each document. Less time was spent reading through the infographics versus the standard material, regardless of whether the infographics were viewed first or second (see Table 4).

Among participants who viewed the infographics first, a total of 90.00% rated its overall appearance as "very good" or "excellent"; in comparison, 78.00% of participants who viewed the standard material first reported similar ratings. After viewing both materials, 86.00% of those who viewed the infographics second rated them as "very good" or "excellent", compared to only 58.00% of participants who viewed the standard materials second. This difference was statistically significant ($p < .01$).

Similarly, participants were significantly more likely to find the infographics easy to understand after viewing both their assigned material and the alternative. Participants who viewed the infographics second rated them an average of 9.30 (out of 10) in comparison to an average rating of 8.22 (out of 10) among those viewing the standard material second ($p < .001$). After both materials had been viewed, participants also provided higher ratings for the infographics than for the standard material when asked about their perceived likelihood of reading the material if provided to them by a doctor, although this relationship was not statistically significant (M = 9.62 (SD = 0.97) vs. M = 9.00 (SD = 2.02); $p = .15$). More than two-thirds of participants (68.00%) preferred the infographics to the standard material, though analyses revealed no differences in preference by participant socio-demographic characteristics or by the health literacy level of participants.

Table 4
Study outcomes, overall and by 1st randomized document exposure.

Outcome	Overall sample (N = 100)	1st Document exposure		P-value
		Infographics (n = 50)	Standard (n = 50)	
Reading duration in minutes M, (SD)				
1st document	8.41 (4.52)	6.94 (3.79)	9.88 (4.74)	0.0009
2nd document	8.87 (5.77)	11.52 (6.62)	6.22 (3.01)	<0.0001
Very good/excellent appearance, n (%)				
1st document	84 (84.00)	45 (90.00)	39 (78.00)	0.10
2nd document	72 (72.00)	29 (58.00)	43 (86.00)	0.002
Very good/excellent quality, n (%)				
1st document	94 (94.00)	48 (96.00)	46 (92.00)	0.68
2nd document	90 (90.00)	46 (92.00)	44 (88.00)	0.74
Easy to understand (1 to 10), M, (SD)				
1st document	8.78 (1.54)	9.02 (1.15)	8.54 (1.83)	0.40
2nd document	8.76 (1.58)	8.22 (1.83)	9.30 (1.05)	0.0005
Likely to read if provided by a doctor (1 to 10), M, (SD)				
1st document	9.44 (1.26)	9.52 (1.30)	9.36 (1.22)	0.27
2nd document	9.31 (1.61)	9.00 (2.02)	9.62 (0.97)	0.15
Satisfied with amount of information (1 to 10), M, (SD)				
1st document	9.18 (1.38)	9.28 (0.93)	9.08 (1.72)	0.66
2nd document	9.14 (1.52)	9.04 (1.67)	9.24 (1.36)	0.74
Preferred Infographics, n (%)	68 (68.00)	29 (58.00)	39 (78.00)	0.03

4. Discussion and conclusions

4.1. Discussion

This study revealed that the cardiac amyloidosis infographics created by our team performed as well as the standard in terms of knowledge acquisition. The infographics were more favorably viewed by participants in terms of their appearance and how easy they were to understand, and they also took less time to read. In comparison to the standard, the infographics were preferred by a majority of participants.

Despite these overall positive findings, we were surprised to find that the infographics did not outperform the standard materials for our

primary outcome (knowledge). There are several reasons why this may have occurred. First, no true "standard" existed for this study. Our team was unable to find a truly comparable patient education material online that covered the same topics as our infographics. While this underscores the need for developing educational materials for cardiac amyloidosis, it also meant that we lacked a true comparator for evaluation purposes. We addressed this by combining online patient education materials from one source and removing sections that were not relevant. This may have created a "curated" standard arm that was easier for patients to interpret and understand than what is currently available online. Moreover, our study sample was relatively small ($N = 100$), and we may have been underpowered to see significant differences in knowledge. Findings indicate that knowledge trended towards being higher among those viewing the infographics versus the standard material. However, we also recognize that to sufficiently understand a complex health condition based on printed material alone, individuals may require multiple viewings of a tangible print material, as opposed to the single viewing assessed in this study. Finally, as revealed in a meta-analysis of print materials for behavior change, it may be that tailored materials and delivery channels to patients facing a diagnosis of cardiac amyloidosis would have had a greater effect on knowledge than the general materials shown to our sample [26]. Other limitations include the fact that results from our small study, which included a cohort with racial demographics that do not fully reflect those of the cardiac amyloidosis population, may not be generalizable. Participants in our sample also had no knowledge of cardiac amyloidosis prior to study enrollment. It is possible that individuals who need information on cardiac amyloidosis may have a higher baseline level of understanding and/or motivation to learn about the condition. Future studies should examine the utility of the infographics among more targeted populations.

Nevertheless, this study had numerous strengths. Our infographics were developed using health literacy best practices, which is supported by a large body of evidence and has been shown to affect the uptake of health behaviors, including preventative behaviors [27]. This study also purposefully included material feedback from diverse, multilevel stakeholders including cardiologists, a patient advocacy group, and lay advisors. Similar processes have been successfully utilized to develop numerous other patient education materials [20,28-30]. Finally, we evaluated the infographics in a rigorous, randomized controlled experiment among a diverse set of participants in the age group largely reflective of the population most affected by cardiac amyloidosis.

Additional research is needed to determine how best to deliver infographics to patients and to ensure adequate comprehension of the condition and associated diagnostic tests among a larger sample. Moreover, as previous studies have revealed the potential for print materials to increase patient-provider communication and patient engagement in a range of conditions [31], additional research is needed to examine the extent to which the infographics increase patient-provider communication about cardiac amyloidosis and enhance engagement in care.

4.2. Innovation

Few patient-friendly education materials on cardiac amyloidosis are available; none, to our knowledge, depict the condition and diagnostic process in the form of readable, understandable, and visually appealing infographics. With the increasing frequency of cardiac amyloidosis diagnosis, infographics may be useful for increasing patient awareness and early detection.

Furthermore, this work is part of a larger innovative initiative, conducted in partnership with industry, to develop patient-friendly educational materials using stakeholder engagement and health literacy best practices. Findings from this example demonstrate the merit in co-developing materials between experts and patients. Lessons learned can be applied to future efforts to develop health education materials.

4.3. Conclusion

Our study resulted in a tangible set of patient-friendly infographics that describe cardiac amyloidosis and the process through which the condition is diagnosed. Incorporating multilevel stakeholder feedback and health literacy best practices, these materials are intended to educate patients about a complex health condition unfamiliar to most adults. Further work will be needed to tailor the materials and ensure appropriate delivery channels are utilized [32].

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Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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Appendix A. Supplementary data

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