Health literacy, health-related quality of life, and atrial fibrillation

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Abstract: Atrial fibrillation (AF) is a chronic heart rhythm disorder associated with significant adverse outcomes. Health-related quality of life (HRQoL) is an established metric of health status in individuals with AF, and health literacy is highly relevant to how individuals experience HRQoL. We conducted a pilot investigation to examine the association of health literacy and health related quality of life (HRQoL) in a limited-sized cohort of individuals with AF, all of whom had AF and were ≥60 years old. We used the Short-Test of Functional Health Literacy in Adults to categorize participants by health literacy status. We used the SF-36 to examine HRQoL in eight subscales and two composite scores, and related health literacy to HRQoL. In our cohort of 40 participants with AF (45% female, age 77.9 ± 8.0 years), 62.5% had inadequate health literacy. However, we did not identify a significant association between health literacy and HRQoL. We expect our limited-sized sample is a chief limitation for why we did not see an association between health literacy and HRQoL in this convenience cohort. Further studies examining health literacy and its impact on patient-centered outcomes in AF are essential.

Keywords: atrial fibrillation; health-related quality of life; health literacy

ABOUT THE AUTHORS

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PUBLIC INTEREST STATEMENT

Atrial fibrillation (AF) is a common and highly morbid condition that is increasing in prevalence with the aging of the general population. AF is a challenging and complex syndrome for patients, combining specialized terminology, long-term monitoring and demanding medication adherence. Even with optimal treatment, patients with AF have increased risk for multiple adverse outcomes. Further, AF contributes to significant social and medical morbidity, and poor health-related quality of life, anxiety and depression are common in AF. Limited health literacy, associated with poor adherence and increased adversity in chronic disease, compounds patient challenges with navigating AF. Improving care for morbid, chronic conditions is a major challenge facing medicine today, and patient-centered outcomes are both central and essential towards that aim. We present a pilot assessment of health literacy and quality of life. AF has myriad challenges for patients, and integrating health literacy is essential to assess quality of life, improve medication adherence, and reduce health care utilization.
1. Introduction
Atrial fibrillation (AF) is the most commonly encountered heart rhythm disorder with an estimated US prevalence of 2.7–6.1 million people (Mozaffarian et al., 2016). AF has profound social and medical costs, and is associated with adverse outcomes that include a 2- to 5-fold increased risk of stroke, heart failure, and mortality (Stewart, Hart, Hole, & McMurray, 2002; Wolf, Dawber, Thomas, & Kannel, 1978). AF treatment requires chronic therapies, daily medication adherence, accurate symptom reporting, and close monitoring and follow-up in order to prevent such adversity. Health literacy is relevant for these aspects of the patient experience of AF. Inadequate health literacy has been related to worse anticoagulation metrics (Oramasionwu et al., 2014) and limited patient understanding of the rationale for anticoagulation (Fang, Panguluri, Machtinger, & Schillinger, 2009). Current AF treatment guidelines emphasize symptom assessment and shared-decision-making to improve “patient-centered care,” yet health literacy has not been well incorporated into models of patient-centered care (Kirchhof et al., 2013).

Health-related quality of life (HRQoL) is further recognized as a relevant outcome in AF treatment and clinical management (Aliot, Botto, Crijns, & Kirchhof, 2014). Reduced HRQoL in individuals with AF has been associated with hospitalization and mortality (Schron, Friedmann, & Thomas, 2014). Health literacy has had limited study in AF and HRQoL, and we consequently investigated the association of health literacy and HRQoL in a limited-sized cohort of individuals with prevalent AF. We hypothesized that inadequate health literacy would be associated with decreased HRQoL relative to those with adequate health literacy. Determining the effects of health literacy on patient-centered outcomes in AF may yield strategies to improve the patient experience of AF and decrease the extensive adversity associated with this heart rhythm disorder.

2. Methods
2.1. Study context
We enrolled individuals with AF as a convenience sample from an ambulatory cardiology clinic affiliated with an urban, safety-net hospital. Patients were screened for eligibility using the electronic medical record before scheduled clinic appointments. We enrolled individuals with age ≥60 years, who were English or Spanish speakers, had the ability to provide informed consent (i.e. no history of dementia or significant cognitive impairment), and a history of AF as documented by the electronic record and demonstrated on an electrocardiogram. In the study, 250 patients who met eligibility criteria were approached at the end of their clinic appointment. Of the potential subjects, 55 were recruited. The most cited reason for refusal of participation was time constraints. Of the 55, 13 were excluded after initial recruitment due to ineligibility that was not detectable from the initial screen (e.g. change in medical condition, mental status, or language barriers). Next, 42 participants completed enrollment with two discontinuations prior to survey completion. Hence, a total of 40 participants were enrolled in this analysis. All participants provided informed consent in English or Spanish, and the study was approved by the Boston University Institutional Review Board.

2.2. Health literacy
We measured health literacy with the Short Test of Functional Health Literacy in Adults (S-TOFHLA), a health literacy assessment tool validated in diverse, chronic conditions and across multiple languages (Apter et al., 2013; Sayah, Majumdar, Egede, & Johnson, 2014). The S-TOFHLA is commonly used and well described elsewhere (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) and consists of two passages with missing keywords that participants select from a list of 4 choices. Functional health literacy is scored from 0–36 with 1 point for each item, and categorized as inadequate (0–16), marginal (17–22), or adequate (23–36).
2.3. Health related quality of life
We assessed HRQoL with the 36-Item Short Form Health Survey (SF-36), an extensively validated tool for quantifying HRQoL that has been used in AF studies (Aliot et al., 2014; Hagens et al., 2004; Howes et al., 2001). SF-36 contains 36 multiple choice questions that measure an individual’s perceived health across eight scales: physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain and general health. The survey was scored based on published scoring instructions (36-Item Short Form Survey Scoring Instructions, 2017). First, participants answered each of the 36 questions based on a pre-coded scale. Next, each item was scored on a 0–100 range and designated to the appropriate category, with higher scores indicating a healthier state. Scores for items in the same category are averaged together to create a category score (i.e. physical functioning). Finally, we generated the physical composite score (PCS) and mental composite score (MCS) by aggregating the eight sub-category scores according to an established scoring algorithm (Farivar, Cunningham, & Hays, 2007; Ware, Kosinski, & Keller, 1994). Composite scores were then compared across study participants.

Materials in Spanish were provided to Spanish-speaking participants. Both the SF-36 and S-TOFHLA are validated in English and Spanish (Arocho & McMillan, 1998; Weiss et al., 2005). Oral portions of the questionnaire were likewise administered in Spanish by a Spanish-speaking member of the research team.

2.3. Other covariates
We collected data on demographics, comorbidities, HRQoL, and health literacy. Demographic data (age, sex, race) were self-reported. Comorbidities were self-reported with complementary ascertainment from electronic health record and included hypertension, hypercholesterolemia, diabetes, and congestive heart failure.

2.4. Study administration
Instruments were presented orally and in written form in English and Spanish by the research administrator, who remained present throughout assessments. Participants completed the health literacy assessment by recording responses on paper. Other instruments were collected on paper. All items were then tabulated and stored in electronic format with participants de-identified.

2.5. Statistical analysis
We examined descriptive statistics by determining the means and standard deviations for continuous variables and categorical distributions for continuous measures. We examined the distribution of the S-TOFHLA in the cohort and found that only one participant scored in the marginal health literacy range. Given our small sample size we combined this individual with the inadequate health literacy category (S-TOFHLA, 0–22); scores ≥23 were categorized as adequate health literacy. Differences between participants with inadequate and adequate health literacy groups were then examined using chi-square and T-tests. This study was approved by the Boston University School of Medicine IRB and all participants provided informed consent. Analyses were conducted using the Stata statistical software (version 12.1, StataCorp, College Station, Texas). The threshold for statistical significance was $p < 0.05$.

3. Results
In total there were 40 participants enrolled in this limited-sized cohort. Table 1 describes the characteristics of the cohort (mean age 78 ± 8.0; 45% women; 27.5% black race; 62.5% inadequate health literacy). Participants with inadequate health literacy were more likely to be of non-white race ($p < 0.05$). In particular, 100% of Hispanic participants had inadequate health literacy. In contrast, 39% of the white participants categorized as such.

Table 2 describes the comparison of the HRQoL measures according to inadequate versus adequate health literacy. In none of the sub-scale measures did we identify a significant difference.
When the composite physical and mental HRQoL scores were examined, we similarly did not find an association with the scores and health literacy. A post hoc power calculation confirmed that our sample size lacked adequate statistical power to determine a significant difference in HRQoL according to health literacy status.

### Table 1. Descriptive characteristics of the cohort, total and by health literacy level

| Variable          | Total cohort (n = 40) | Inadequate health literacy (n = 25) | Adequate health literacy (n = 15) | χ² or t-test |
|-------------------|----------------------|-------------------------------------|----------------------------------|-------------|
| Age (y)           | 77.9 ± 8.0           | 78.7 ± 7.0                          | 76.5 ± 9.6                       | = −0.84     |
|                   |                      |                                     |                                  | p = 0.80    |
| Women             | 18 (45)              | 11 (61.1)                           | 7 (38.9)                         | 0.03        |
|                   |                      |                                     |                                  | p = 0.87    |
| Race              |                      |                                     |                                  |             |
| White             | 18 (45.0)            | 7 (28.0)                            | 11 (73.3)                        | 10.89       |
|                   |                      |                                     |                                  | p < 0.05    |
| Black             | 11 (27.5)            | 7 (28.0)                            | 4 (26.7)                         |             |
| Hispanic          | 9 (22.5)             | 9 (36.0)                            | 0 (0)                            |             |
| Other             | 2 (5.0)              | 2 (8.0)                             | 0 (0)                            |             |
| Comorbidities     |                      |                                     |                                  |             |
| Hypertension      | 36 (90.0)            |                                     |                                  |             |
|                   |                      |                                     |                                  | t = −0.63   |
| Hypercholesterol- | 33 (82.5)            |                                     |                                  | p = 0.73    |
| emia              |                      |                                     |                                  |             |
| Congestive heart  | 14 (35.0)            |                                     |                                  |             |
| failure           |                      |                                     |                                  |             |
| Diabetes          | 7 (17.5)             |                                     |                                  |             |

Note: Continuous variables summarized as mean ± standard deviation and categorical variables as N (%).

### Table 2. Comparison of SF-36 domains by health literacy status in individuals with atrial fibrillation

| Domain                | Inadequate health literacy (n = 25) | Adequate health literacy (n = 15) | t-test (p-value) |
|-----------------------|--------------------------------------|----------------------------------|-----------------|
| Physical functioning  | 56.8 ± 35.6                          | 58.0 ± 23.2                      | 0.11 (p = 0.45) |
| Physical health, role | 51.0 ± 43.6                          | 50.0 ± 47.3                      | −0.06 (p = 0.53) |
| limitations           |                                      |                                  |                 |
| Emotional health, role| 82.7 ± 34.9                          | 68.9 ± 42.7                      | −1.11 (0.86)    |
| limitations           |                                      |                                  |                 |
| Energy/fatigue        | 59.8 ± 30.0                          | 53.1 ± 23.1                      | −0.74 (p = 0.77) |
| Emotional well-being  | 74.2 ± 24.8                          | 78.4 ± 18.9                      | 0.56 (p = 0.29) |
| Social functioning    | 72.5 ± 36.6                          | 78.3 ± 30.8                      | 0.52 (p = 0.30) |
| Pain                  | 66.3 ± 33.6                          | 72.0 ± 22.9                      | 0.58 (p = 0.28) |
| General health        | 63.4 ± 27.4                          | 53.0 ± 15.5                      | −1.34 (p = 0.91) |
| Physical composite    | 50.3 ± 10.2                          | 49.6 ± 8.1                       | −0.23 (p = 0.59) |
| score                 |                                      |                                  |                 |
| Mental composite      | 50.34 ± 9.4                          | 49.4 ± 7.5                       | −0.32 (p = 0.62) |

Note: All scores presented as mean ± SD.

According to health literacy status. When the composite physical and mental HRQoL scores were examined, we similarly did not find an association with the scores and health literacy. A post hoc power calculation confirmed that our sample size lacked adequate statistical power to determine a significant difference in HRQoL according to health literacy status.

### 4. Discussion

We enrolled a limited-sized, convenience cohort in order to investigate health literacy and HRQoL in individuals with AF. We specifically hypothesized that individuals with inadequate health literacy would have worse HRQoL compared to those with adequate health literacy, but did not identify such
an association in this small-sized cohort. Our analysis was challenged significantly by its small size and limited statistical power.

However, our hypothesis merits continued investigation in larger cohorts in order to improve the clinical care and management of AF. Individuals with AF are burdened by symptoms, adherence to long-term therapies and adverse outcomes that impact HRQoL (Freeman et al., 2015; Sandhu et al., 2016). Many individuals with AF are poorly informed about the condition and its treatment options and health risks (Lane, Ponsford, Shelley, Sirpal, & Lip, 2006). Health literacy is consequently highly relevant towards how individuals experience AF by interpreting and reporting symptoms and participating in treatment decisions. HRQoL has been advanced as a patient-centered outcome in AF. Its successful use as a metric requires understanding how health literacy may affect and mediate such a measure.

The preliminary investigation reported here has several limitations, and we have emphasized foremost the limited statistical power due to the small-sized cohort (n = 40). Second, the participants comprised a convenience sample enrolled from a single clinical setting, thereby limiting the generalizability of the findings. Third, we included limited covariates and cannot exclude residual confounding. Symptoms and family income, for example, were not included in our analyses. It is also possible that participants had multiple comorbidities, not included here, that may influence their HRQoL. Fourth, while we selected well-validated measures health literacy and HRQoL, we cannot exclude that such tools have unmeasured biases in our setting and patient cohort.

As the prevalence of AF and its social and medical costs increase (Mozaffarian et al., 2016), identifying ways to improve HRQoL in individuals with AF may enhance patient-centered care and reduce strain on the health care system. AF is a challenging condition with a strong adverse impact on individuals HRQoL. The relation between health literacy and HRQoL in individuals with AF warrants further investigation.

Funding
This work was supported by [grant number 2015084] from the Doris Duke Charitable Foundation.

Competing Interests
The authors declare no competing interest.

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Citation information
Cite this article as: Health literacy, health-related quality of life, and atrial fibrillation, Kara E. Montbleau, Deandre King, Lori Henault & Jared W Magnani, Cogent Medicine (2017), 4: 1412121.

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