

# Patient Perception of Treatment Experience Observed During Routine Specialty Pharmacy Interactions for ATTR-CM

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## BACKGROUND

Patients with transthyretin amyloid cardiomyopathy (ATTR-CM) require long-term therapy and ongoing engagement with care teams. Health system specialty pharmacies (HSSPs) maintain frequent contact through medication fulfillment and support services. During these interactions, patients may share perceptions about their treatment experience that are influenced by disease progression, comorbidities, expectations, or other external factors; however, longitudinal changes in patient perception in ATTR-CM are not well described. Understanding changes in patient perception of treatment experience may help HSSPs identify opportunities to reinforce education, align expectations, and provide counseling. The objective was to describe patient perception of treatment experience observed during routine specialty pharmacy interactions among tafamidis-treated ATTR-CM patients and identify opportunities for HSSP intervention.

## METHODS

**Design and Inclusion Criteria:** Retrospective observational analysis of adult patients newly initiating tafamidis and filling prescriptions through a national network of HSSPs from May 2019 to February 2026. Patients were included if they had a baseline and at least one follow-up NYHA class recorded in the patient management system.

- During every routine refill, pharmacy liaisons documented patient perception of treatment experience using a single, non-validated question: **How has \_\_\_\_ (specialty medication) helped you manage your \_\_\_\_ (condition) from very well (5) to very poor (1)?**
- Pharmacists engage patients prior to therapy initiation, at designated time points, and as needed throughout therapy based on clinical discretion.

**Outcomes:** Number and type of patient perception change events, therapy duration, medication adherence measured by average adjusted proportion of days covered (PDC), total pharmacist touchpoints, and duration between touchpoints

**Analysis:** Patient perception scores were grouped into three categories: positive, neutral, and negative (**Table 1**). Change events were determined from differences in rating categories between responses, and patients were categorized based on what types of change events occurred: never changed, decrease only, increase only, and both.

### Definitions:

- Change Event:** A difference in patient perception rating from one category to another
- Duration of Therapy:** Days between the first and last fill
- Pharmacist Touchpoints:** All initial, follow-up, onboarding, and intervention activities recorded between the first and last fills

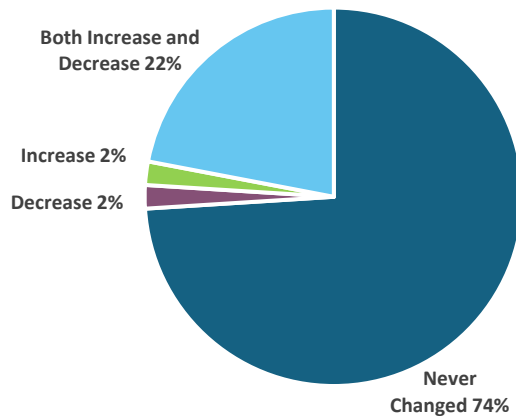
**Table 1: Patient Perception Response Scale**

| Response      | Category |
|---------------|----------|
| 5 (Very Well) | Positive |
| 4 (Well)      |          |
| 3 (Neutral)   |          |
| 2 (Poor)      | Negative |
| 1 (Very Poor) |          |

## RESULTS

A total of 1032 patients meeting the inclusion criteria were identified. Overall, 74% of patients did not have a change event in patient perception during therapy (**Figure 1**), and **Table 2** summarizes patient characteristics. Patients who had both increase and decrease change events in patient perception had the highest average number of pharmacist touchpoints during therapy (**Figure 2**).

**Figure 1: Changes in Patient Perception (N=1032)**

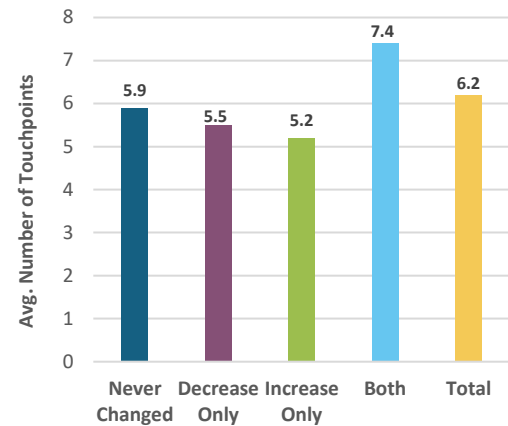


**Table 2: Patient Characteristics**

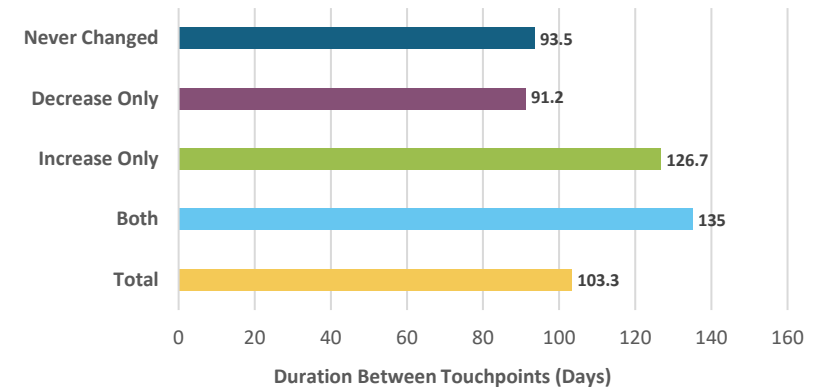
| Characteristic               | Never Changed (761) | Decrease Only (23) | Increase Only (23) | Both (225) | Total (1032) |
|------------------------------|---------------------|--------------------|--------------------|------------|--------------|
| Age at initial fill (years)* | 80.3                | 79.5               | 82.5               | 79.1       | 80           |
| Sex (n, %)                   |                     |                    |                    |            |              |
| M                            | 591 (75.2)          | 16 (2)             | 15 (1.9)           | 164 (20.9) | 786 (76)     |
| F                            | 170 (69.1)          | 7 (2.8)            | 8 (3.3)            | 61 (24.8)  | 246 (24)     |
| Baseline NYHA Class (n, %)   |                     |                    |                    |            |              |
| I                            | 84 (80)             | 0                  | 0                  | 21 (20)    | 105 (10)     |
| II                           | 290 (71)            | 8 (2)              | 10 (2.5)           | 100 (24.5) | 408 (40)     |
| III                          | 369 (74)            | 13 (3)             | 13 (3)             | 99 (20)    | 494 (48)     |
| IV                           | 18 (72)             | 2 (8)              | 0                  | 5 (20)     | 25 (2)       |
| Duration on Therapy (days)*  | 528.4               | 512.3              | 467.5              | 878.5      | 603.5        |
| Adjusted PDC*                | 98.1%               | 96.8%              | 97.5%              | 97.4%      | 97.9%        |
| Average Change Events (n)    | 0                   | 1                  | 1                  | 3.4        | 0.8          |

\*Average

**Figure 2: Pharmacist Touchpoints**



**Figure 3: Duration Between Pharmacist Touchpoints**



## CONCLUSION

- In this real-world description of tafamidis patients, changes in patient perception of treatment experience were observed, however a majority of patients did not experience a change event during therapy.
- Patients maintained high medication adherence over the course of long-term therapy.
- Recognizing changes may support timely education and counseling tailored to patient needs and highlight an opportunity for HSSPs to proactively assess patients.
- These descriptive findings inform HSSP practice insights rather than evaluating or validating patient-reported measurements.