Presentation of:

Amyloidosis Appointment Companion: A Virtual Healthcare Tool to Optimize Shared Decision Making and Improve Patient Experience and Provider Satisfaction for Telehealth and In-Person Appointments

Isabelle Lousada[2], Robyn Himick[2], Jason Shore[3], Adam Sodowick[3], Lisa Mendelson[1], Vaishali Sanchorawala[1]

[1]Boston University School of Medicine and Boston Medical Center, Boston, MA, USA,

[2]Amyloidosis Research Consortium, Newton, MA, USA,

[3]Patient Discovery Solutions Inc, Boston, MA

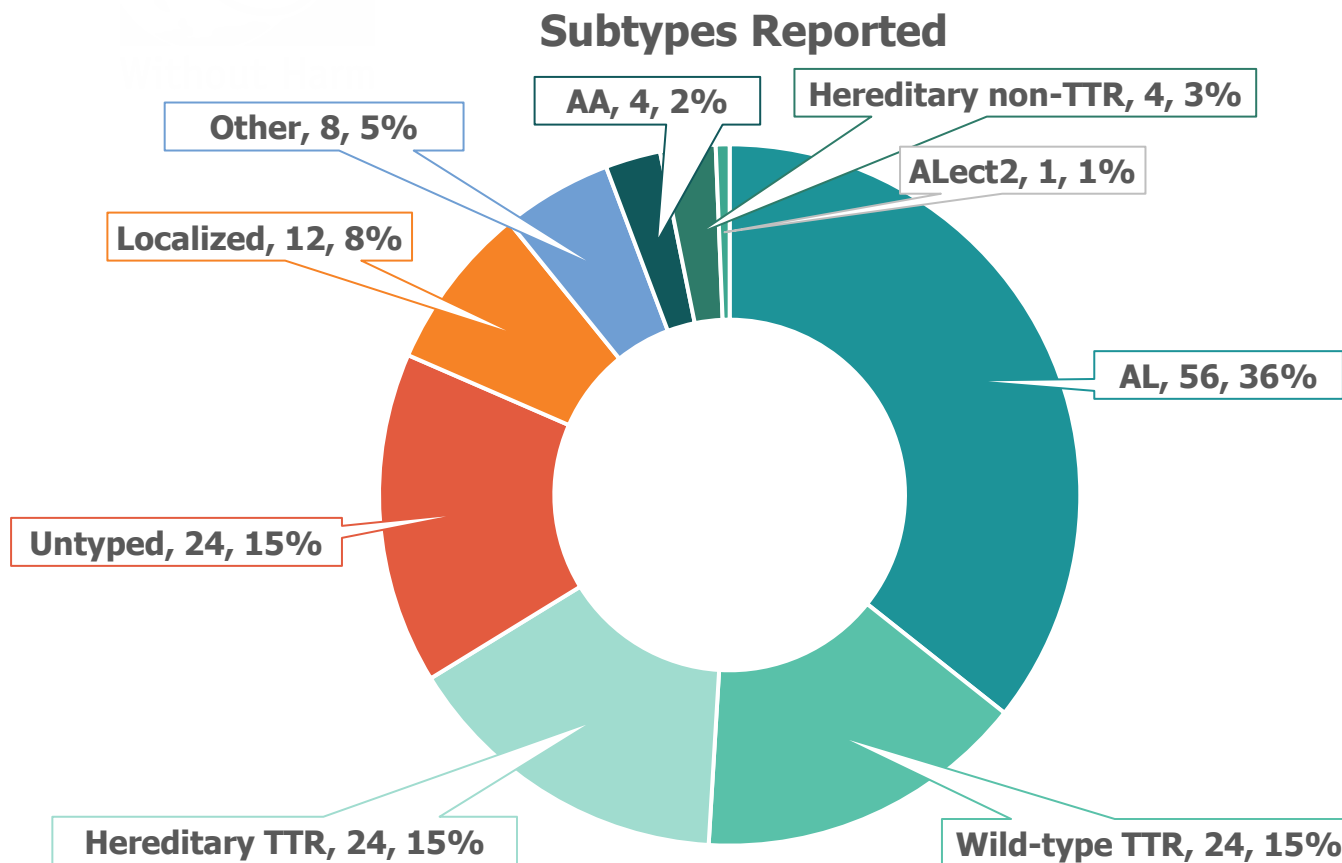**Presented at:**

62nd ASH Annual Meeting | Saturday, December 5, 2020

Disclosures

We have no conflicts of interest to disclose.

Background/Methods

- Patients with amyloidoses come into their appointments often overwhelmed by:
  - the complexities of symptoms
  - treatment options
  - management of their care team

- The Amyloidosis Appointment Companion (AAC) was created by the Amyloidosis Research Consortium (ARC) in collaboration with Patient Discovery to help patients:
  - identify goals of care
  - identify changes in their condition
  - identify challenges they are facing
  - share these with their health care providers
  - create a synergy with their clinicians to guide discussion and development of their treatment plan

- Launched at Boston University Medical Center (BUMC) in January 2020 and integrated into appointments
  - additional telehealth-specific features were added in response to COVID-19
  - prior to appointment patients are asked to complete the AAC which captures:
    - vitals, labs, medications, goals of care, symptoms and side effects, quality of life measures and treatment satisfaction and preferences

Characteristics of 157 Patients

Characteristics	Patients
Age, mean (SD)	65.9 (13.0)
Patient, n(%)	153 (97.5)
Caregiver, n(%)	4 (2.5)
Years since diagnosis (n=133), mean (SD)	4.8 (4.9)
Years from symptoms to diagnosis (n=133), mean (SD)	2.1 (4.5)

Subtypes Reported

- AA, 4, 2%
- Hereditary non-TTR, 4, 3%
- Other, 8, 5%
- ALect2, 1, 1%
- Localized, 12, 8%
- AL, 56, 36%
- Untyped, 24, 15%
- Hereditary TTR, 24, 15%
- Wild-type TTR, 24, 15%

Virtual Patient Engagement

Amyloidosis
Research
Consortium

- **83.4%** Completion Rate

- Average Time Using the AAC is **18.8** minutes

- **27.6%** of Patients Had Telehealth Appointments

- **45.9%** of Patients Used AAC on Mobile

- The AAC enhanced patient and physician communication for both in-person and telehealth visits*
  - Telehealth appointments represent 27.6% of all patients who added appointments to Pathfinder since outbreak of COVID-19 pandemic
  - Telehealth appointments peaked at 34.9% of total appointments

Appointment Type	Since COVID-19 pandemic outbreak	March - August	August - November
In-person	92	41	51
Telehealth	35	22	13
Telehealth percentage	27.6%	34.9%	20.3%

*Prior to the outbreak of COVID-19 pandemic, BUMC did not have any telehealth visits

Patient Preparedness for the Appointment

Patient Insights

Activity	Time spent (minutes)
Discussion Topics	3.5
Goals of Care	2.3
Quality of Life	1.7
Treatment Satisfaction	0.8
Total Time	**8.3**

The AAC emphasizes patient engagement to facilitate patient communication and involvement in decision making, as well as helping providers understand their patients' preferences and goals of care.

Appointment Preparation

Activity	Time spent (minutes)
Medication Reconciliation	6.1
Lab tracking	1.1
Telehealth preparation	0.6
Vitals Entry	0.4
Total Time	**8.2**

Providers reported use of the AAC led to greater efficiency during telehealth appointments allowing more time during the appointment to focus on delivering personalized care.
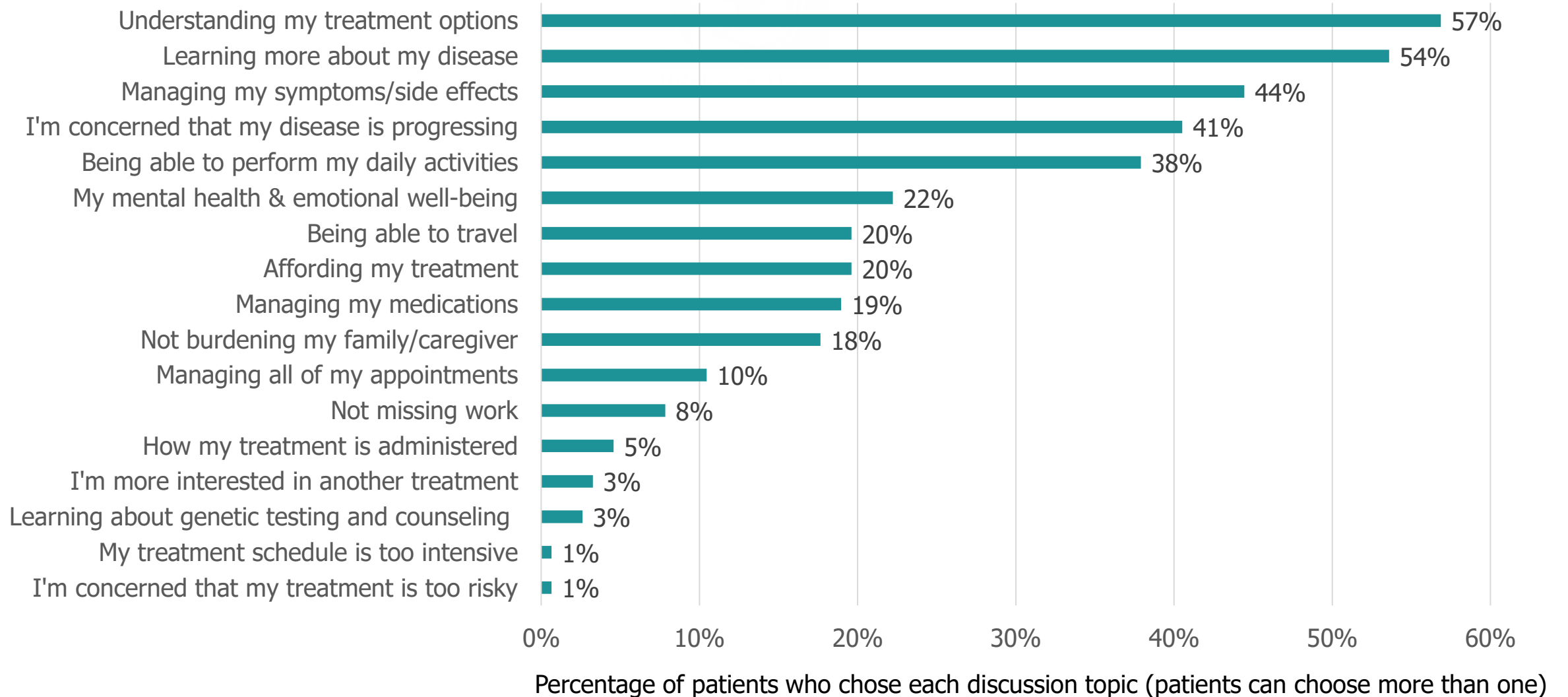
Provider Satisfaction

'My favorite part of the AAC is the medication list! Medication reconciliation prior to the visit saves me at least 10 minutes! Entry of vital signs on AAC makes telemedicine visits more meaningful. Partnering with patients in their care is the most satisfying experience!'

- Dr. Vaishali Sanchorawala

Three providers within the Amyloidosis Center at BUMC independently reported enhanced satisfaction with outcome of appointments as a result of patients having used the AAC.

Discussion Topics for Appointment

Topic	Percentage
Understanding my treatment options	57%
Learning more about my disease	54%
Managing my symptoms/side effects	44%
I'm concerned that my disease is progressing	41%
Being able to perform my daily activities	38%
My mental health & emotional well-being	22%
Being able to travel	20%
Affording my treatment	20%
Managing my medications	19%
Not burdening my family/caregiver	18%
Managing all of my appointments	10%
Not missing work	8%
How my treatment is administered	5%
I'm more interested in another treatment	3%
Learning about genetic testing and counseling	3%
My treatment schedule is too intensive	1%
I'm concerned that my treatment is too risky	1%

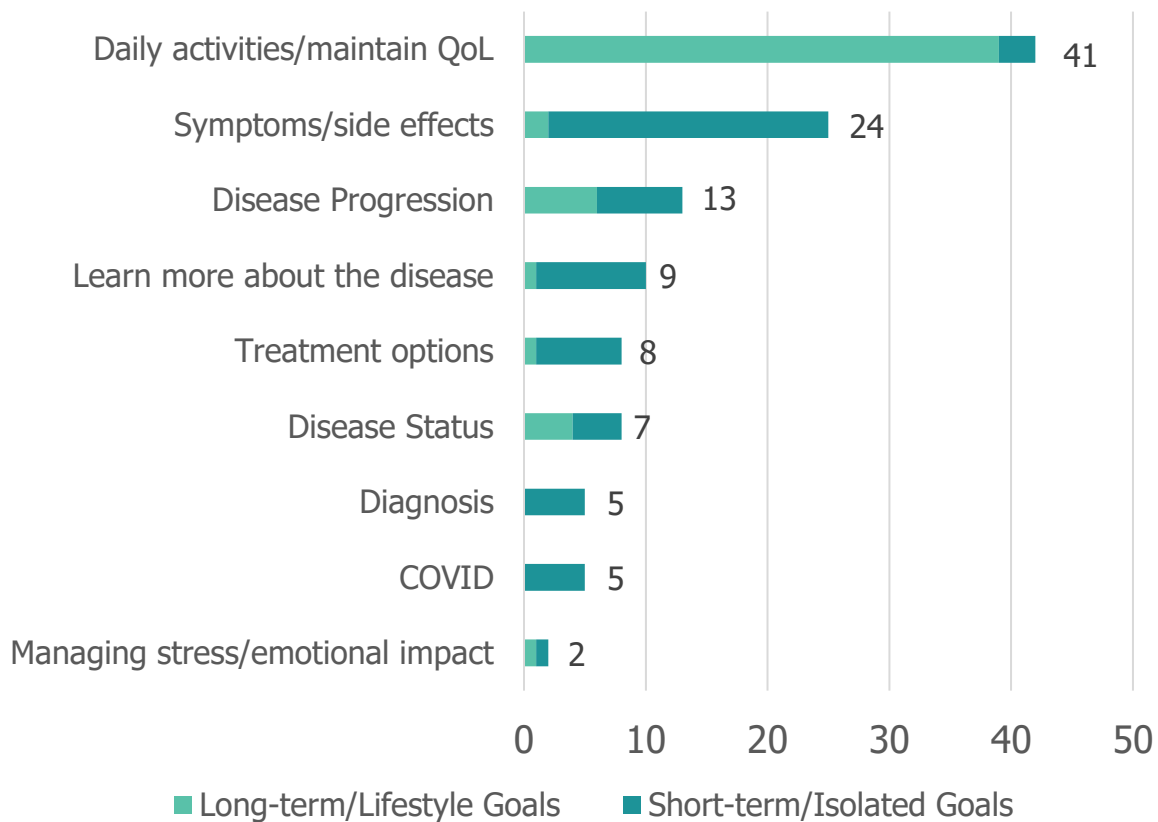Percentage of patients who chose each discussion topic (patients can choose more than one)
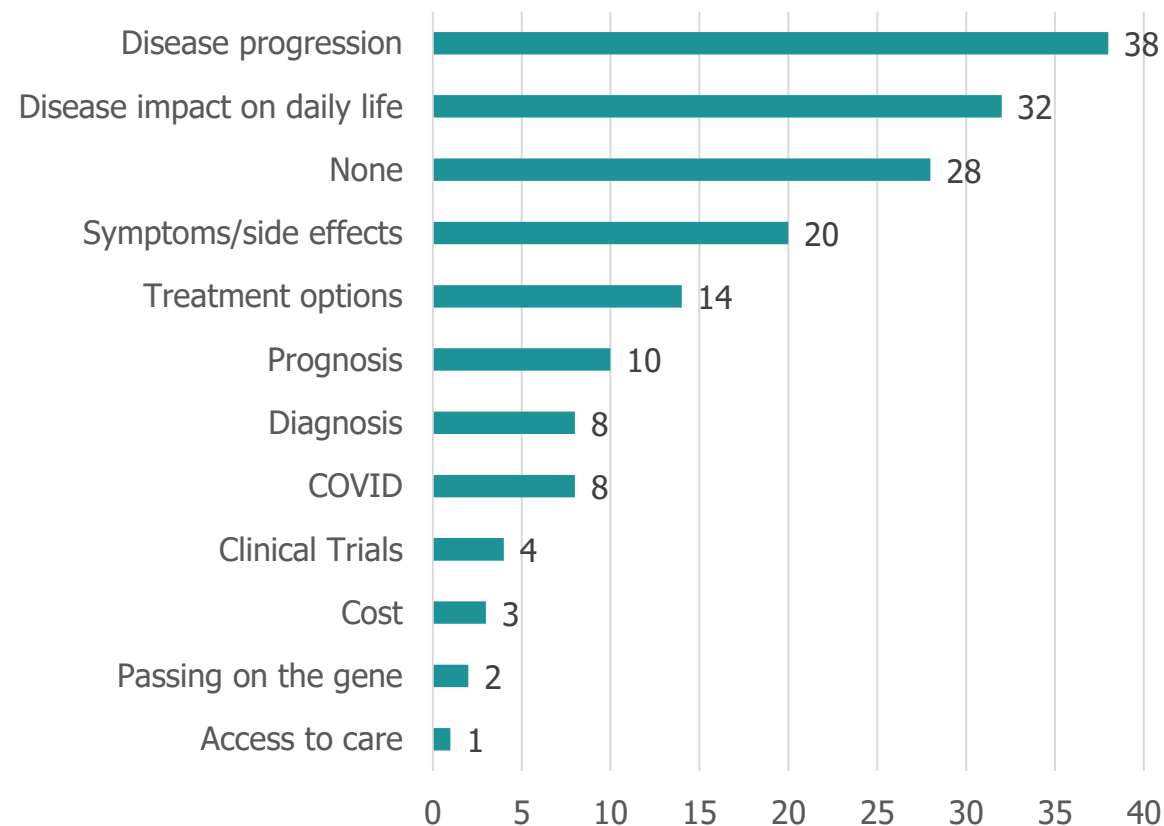
Goals of Care and Overriding Worry/Concerns

"Your goals of care are examples of specific things you would like to accomplish with the help of your care plan and can include a wide range of activities from performing simple daily tasks to taking part in major life events."

"One last question. Many patients have an overriding worry or concern. Please let your care team know what this is in your own words, so they can be sure to address it at your next visit."
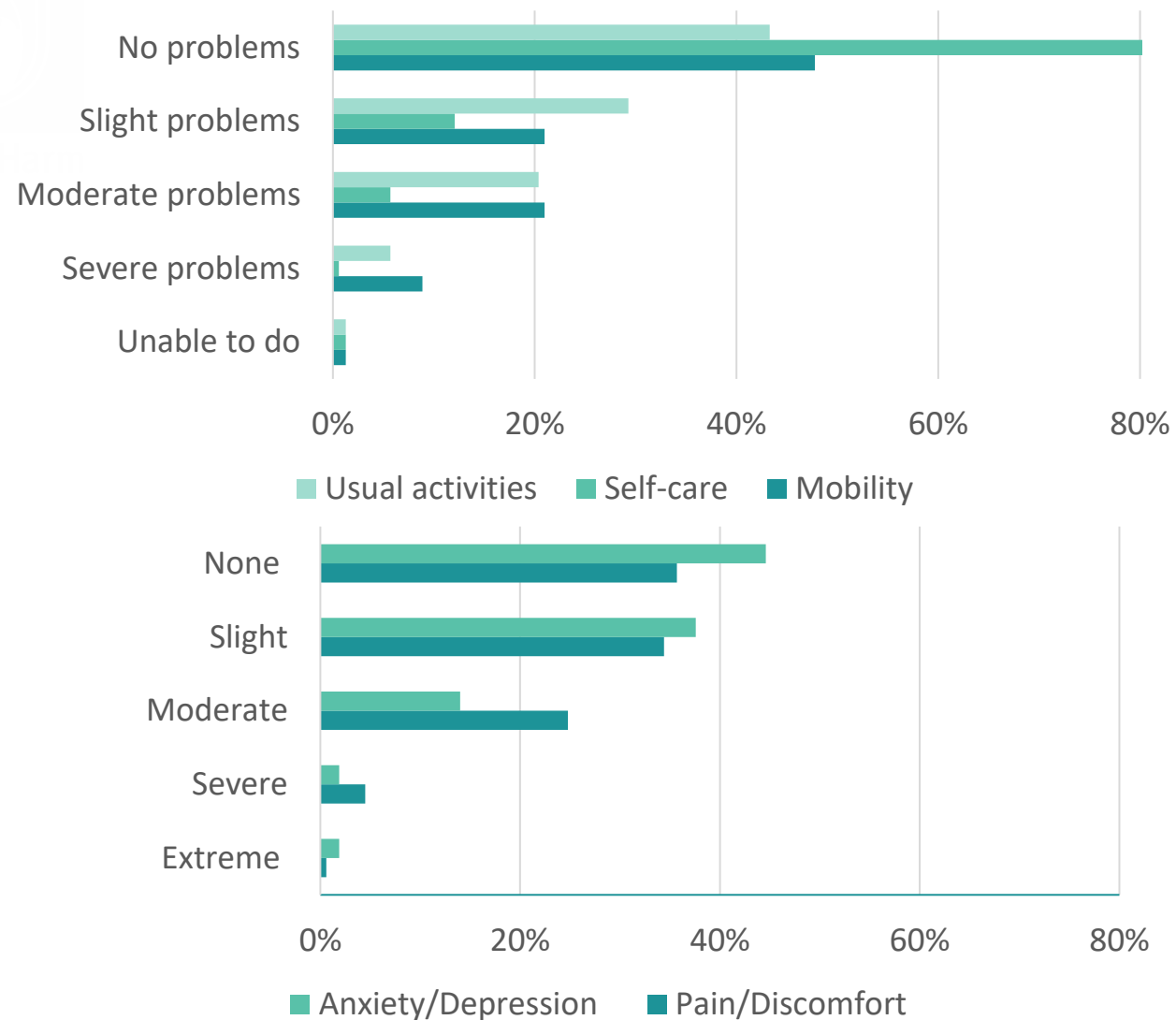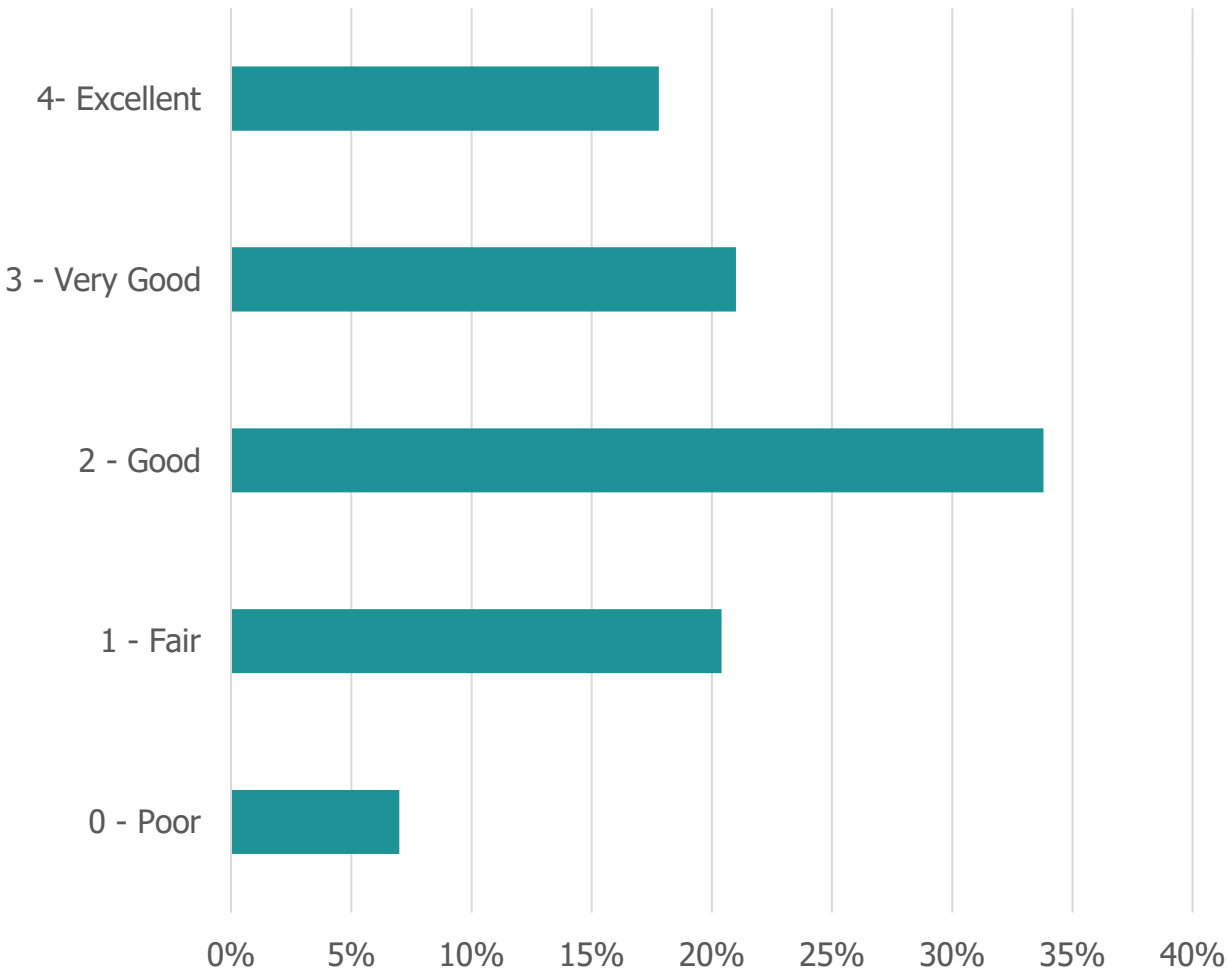
Goals of Care

Category	Value
Daily activities/maintain QoL	41
Symptoms/side effects	24
Disease Progression	13
Learn more about the disease	9
Treatment options	8
Disease Status	7
Diagnosis	5
COVID	5
Managing stress/emotional impact	2

■ Long-term/Lifestyle Goals   ■ Short-term/Isolated Goals

Overriding Worry/Concern

Category	Value
Disease progression	38
Disease impact on daily life	32
None	28
Symptoms/side effects	20
Treatment options	14
Prognosis	10
Diagnosis	8
COVID	8
Clinical Trials	4
Cost	3
Passing on the gene	2
Access to care	1

Quality of Life Impacted by Amyloidosis

"How have you been feeling since last appointment?"

Conclusions

- The AAC emphasizes patient engagement to facilitate patient communication and involvement in decision making, as well as helping providers understand their patients' preferences and goals of care.

- Providers reported use of the AAC led to greater efficiency during both telehealth and in-person appointments, allowing more time during the appointment to focus on delivering personalized care.

- The AAC allows for improved patient to physician communication particularly during a time of increased telehealth visits due to the COVID-19 pandemic.

- Providers within the Amyloidosis Center at BUMC independently reported enhanced satisfaction with outcomes of appointments as a result of patients having used the AAC.

- Insights from these data provide powerful information that may help improve the design of clinical trials, the focus of research, and evaluation for patient support programs.