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## Research article

# A mixed method approach to understanding the impact of COVID-19 on patients with or at risk for aortic dissection



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## ARTICLE INFO

## ABSTRACT

Aortic dissection (AD) is a life-threatening rare disease that occurs as a spontaneous tear in the wall of the aorta. Survivors of AD go on to have a chronic disease process that requires lifelong follow-up and management. Although the COVID-19 pandemic has strained health systems and impacted practice in the United States, the effects of these impacts on people living with or at risk for AD is not well understood. This mixed methods project examined the experiences of people in the AD community during the COVID-19 pandemic between March and October 2020. Results reveal that the AD community lacked clear guidance on the role aortic health status plays in COVID-19 risk and experienced significant disruptions in aortic healthcare. At the same time, the new expansion in access to medical care with telehealth conferred unforeseen benefits in the form of reduced barriers for access to specialized aortic health care.

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## 1. Introduction

Aortic dissection (AD) is a life-threatening rare disease affecting an estimated 4–5 per 100,000 individuals in the United States [1]. Survivors of AD go on to have a chronic disease process that requires ongoing management, including anti-hypertension therapy, avoidance of physical and psychological stress, lifelong surveillance for aneurysmal degeneration of the aorta, and possible need for operative interventions. To address the needs of those living with or at risk for AD, we established the Aortic Dissection Collaborative (AD Collaborative) in 2019. Funded by a Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute, the AD Collaborative is led by a wide range of patient, family member, researcher, clinician, surgeon, and advocacy organization stakeholders. The aim of the AD Collaborative is to improve the management of AD and the quality of life for people living with or at risk for AD [2].

As COVID-19 took hold across the world in early 2020, AD Collaborative stakeholders reported that the AD community was worried about susceptibility to COVID-19 and the ability to access necessary ongoing monitoring and treatment. Health care provider stakeholders noted an apparent decrease in patients presenting at emergency departments with acute aortic symptoms and stated concern that people with or at risk for AD may not be accessing urgently needed care [3,4]. Stakeholders further noted that the lack of evidence about risk for COVID-19 conferred by AD represents a critical knowledge gap that carries significant ramifications for the ongoing care that living with or at risk for this rare disease requires.

The objective of the project reported here was therefore to examine how the COVID-19 pandemic has affected people living with or at risk for AD, in critical areas related to access to ongoing care, necessary monitoring, procedures, and medications; patterns of care-seeking behavior for ongoing and urgent/emergent aortic health needs; and knowledge, attitudes, and practices related to risk for coronavirus.

## 2. Methods

This project used survey and interviews to understand the experiences of the AD community during the COVID-19 pandemic, employing a sequential convergent mixed methods design in which quantitative and qualitative findings were integrated into a synthesized final analysis [5–7]. AD Collaborative patient and stakeholder advisory group members were involved in the development of research questions, project protocols, survey tools, and interview guides, and collaborated on data analysis. This project was submitted to the University of Washington Institutional Review Board for ethics review and an exempt determination was issued on 7/27/2020 (IRB #8826). Respondents gave consent by clicking on “agree to participate in this survey” prior to opening the survey.

### 2.1. Quantitative methods

The survey was distributed between July and September 2021 inclusive. AD Collaborative members and partner organizations distributed the survey link through their organizational

listservs and websites, online patient support groups, and professional and personal networks within the AD Community. Survey data were collected and managed using REDCap electronic data capture tools hosted by University of Washington Institute of Translational Health Sciences [8,9]. Survey questions addressed experiences during the COVID-19 pandemic beginning in March 2020 (see Appendix A). Domains included the impact of COVID-19 on clinic appointments, scheduled surgery, and emergency care; worries related to COVID-19 impact on aortic health care; personal experience with COVID-19; experiences with telehealth; and demographics and willingness to participate in interviews. Questions regarding experiences with telehealth were adapted from the Medical University of South Carolina Telehealth Survey [10]. People with or at risk for AD (patients) and family members/caregivers of patients (care partners) 18 years and older were eligible to participate in the survey, regardless of geographical location. Participants were assessed for eligibility by answering screening questions before entering the survey itself; those who were eligible were then prompted to complete the survey.

## 2.2. Qualitative methods

Survey respondents who indicated willingness to participate in in-depth semi-structured interviews with a member of our team, who listed their country of residence as the United States, and who provided contact information were eligible to participate in interviews. We selected a purposive sample from the eligible pool of survey respondents to ensure adequate inclusion of participants based on aortic health status (ie, diagnosis of AD and risk for AD), underlying risk factors for AD, race and ethnicity, sex, and geographic region. Care partner sampling included family members and caregivers of both minors and adults. We oversampled for groups who are traditionally underrepresented in research and who are disproportionately affected by poor outcomes associated with AD, and to ensure representation of a wide range of perspectives reflective of the diversity of the AD community. The research team reviewed demographic and diagnostic characteristics of potential participants and used the sampling criteria to select 42 patients and 22 care partners to invite to participate in interviews.

The semi-structured interview guide was developed in partnership with the AD Collaborative's patient and stakeholder partners. Interviews were conducted by the project's lead qualitative researcher via HIPAA (Health Insurance Portability and Accountability Act)-compliant, secure video conferencing software, and were audio recorded and transcribed. A team of three researchers analyzed the interview data using Dedoose qualitative analysis software [11]. The analysis team included the lead qualitative researcher, a second analyst with expertise in qualitative research, and a patient advocate with expertise in the lived experience of AD. Analysis proceeded iteratively, beginning with a set of *a priori* codes derived from relevant survey results and discussion with AD Collaborative stakeholders to identify salient dimensions for analysis from the perspective of the AD community. Codes were added inductively as salient topics emerged through

the analysis process. The analysis team used consensus coding methodology, with the lead qualitative researcher resolving non-concordant codes, followed by thematic analysis to identify salient cross-cutting themes within the coded data [12,13].

## 2.3. Integration of quantitative and qualitative findings

The research team integrated the results of quantitative and qualitative analyses, assessing convergence and/or divergence of survey and interview results [6,7]. Integrated results were presented to the AD Collaborative patient and stakeholder advisory groups to refine the analysis and gather insight on critical areas to define as priority for policy and practice implications. Integrated results were then presented via live webinar to the broader AD community, including patients, care partners, clinicians, advocacy organizations, and researchers [14]. The webinar was designed as a modified member checking exercise adapted from methods employed by Naidu and Prose in which research findings are presented back to the community for discussion and validation [15,16]. During the webinar, the project leads presented and facilitated discussion about the findings. After discussion, participants took a brief poll asking them to rate the degree to which the findings reflected their own experiences. Feedback provided during this session was used to finalize the analysis and to evaluate the applicability of findings to the larger AD community.

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## 3. Results

The survey was disseminated between August 4, 2020 and October 31, 2020. A total 416 US patients and 74 US care partners completed the survey. A total of 23 of the 64 people invited participated in in-depth semi-structured interviews, including 17 patients and 6 care partners. The sections of the interviews that addressed impacts of COVID-19 were included in the current analysis; the remaining data were analyzed separately and are reported elsewhere. Demographics of survey respondents and interview participants are detailed in Table 1.

Integrated analysis of the survey and interview results yielded three synthesized findings that highlight how the COVID-19 pandemic impacted the AD community between March and October 2020 (Table 2). We present these findings as themes that revealed the need for clear guidance on whether aortic health status confers risk related to COVID-19, how the pandemic made an already complex care environment even more difficult to navigate, and the ways access to telehealth changed the landscape of care within the AD community.

### 3.1. Theme 1: Navigating risk, coping with uncertainty

Survey results revealed that although most respondents reported they did not believe their aortic health status placed them at increased risk for contracting COVID-19, many more believed aortic health status conferred increased risk for the poor outcomes associated with COVID-19 in the event they

**Table 1 – Demographic characteristics of survey and interview participants.**

Characteristic	Survey, n (%)		Interviews, n (%)	
	Patients (n = 416)	Care partners <sup>a</sup> (n = 74)	Patients (n = 17)	Care partners <sup>a</sup> (n = 6)
<b>AD diagnosis<sup>b</sup></b>				
Type A	83 (20)	7 (9)	4 (24)	0
Type B	100 (24)	10 (14)	4 (24)	3 (50)
Type unknown	73 (18)	15 (20)	2 (12)	0
At risk	202 (49)	45 (61)	8 (47)	3 (50)
<b>Risk condition<sup>b,c</sup></b>				
Bicuspid aortic valve	16 (8)	1 (2)	1 (13)	1 (17)
Family history	79 (39)	9 (20)	3 (38)	0
Loeys-Dietz syndrome	22 (11)	4 (9)	1 (13)	0
Marfan syndrome	116 (57)	25 (56)	1 (13)	2 (33)
Vascular Ehlers-Danlos syndrome	25 (12)	9 (20)	2 (25)	1 (17)
Other	30 (15)	3 (7)	0	0
<b>US region</b>				
West	119 (27)	18 (24)	5 (29)	2 (33)
Midwest	101 (24)	23 (31)	4 (24)	2 (33)
Northeast	76 (18)	10 (14)	5 (29)	1 (17)
South	118 (28)	23 (31)	3 (18)	1 (17)
Unknown	2 (0.4)	0	0	0
<b>Residence</b>				
Urban	85 (20)	17 (23)	3 (18)	3 (50)
Suburban	153 (37)	23 (31)	6 (35)	3 (50)
Exurban	118 (28)	22 (30)	7 (41)	0
Rural	60 (14)	12 (16)	1 (6)	0
<b>Age<sup>d</sup></b>				
<18 y	NA	28 (39)	n/a	3 (50)
18–40 y	123 (30)	23 (31)	7 (41)	1 (17)
40–59 y	186 (45)	17 (23)	6 (35)	1 (17)
60–79 y	105 (25)	10 (14)	4 (24)	1 (17)
NA	2 (0.4)	0	0	0
<b>Sex/gender</b>				
Female	283 (68)	21 (28)	12 (71)	3 (50)
Male	130 (31)	53 (72)	5 (29)	3 (50)
NA	2 (0.4)	0	0	0
Trans/nonbinary	7 (2)	NA	0	NA
<b>Race/ethnicity<sup>b</sup></b>				
American Indian or other Indigenous	3 (0.7)	1 (1)	1 (6)	1 (17)
Asian	13 (3)	1 (1)	2 (12)	0
Black or African American	12 (3)	4 (5)	2 (12)	0
Latinx or Hispanic	17 (4)	5 (7)	4 (24)	1 (17)
Middle Eastern or North African	2 (0.5)	0	1 (6)	0
Native Hawaiian or Pacific Islander	1 (0.1)	0	0	0
White	369 (89)	68 (92)	10 (59)	6 (75)
Multiracial or multiethnic	14 (3)	5 (7)	3 (18)	2 (33)
NA	10 (2)	0	0	0
Other	4 (1)	0	0	0

NA, not applicable.

<sup>a</sup> Care partner responses reflect the family member in question.

<sup>b</sup> Respondents were able to enter more than one response in this category.

<sup>c</sup> Only collected for respondents at risk for AD; survey: patients n = 202, care partners n = 45, interviews: patients n = 8, care partners n = 3.

<sup>d</sup> In surveys, four care partner respondents listed ages for two family members.

did contract it. Regarding risk related to aortic health status for contracting COVID-19, 28.8% of patients and 31.1% of care partners believed they were at increased risk. An additional 15.9% of patients and 18.9% of care partners were unsure. Regarding risk for the poor outcomes associated with COVID-19, 55.0% of patients and 47.3% of care partners believed their aortic health status placed them at increased risk; a further 19.2% of patients and 28.4% of care partners were unsure.

Regarding adoption of protective behaviors to reduce risk of contracting COVID-19, both patients and care partners reported high adherence to public health recommendations. This included social distancing (92.1%, 94.6%), wearing masks or face coverings (95.0%, 91.9%), and limiting or not attending outdoor and indoor gatherings with individuals outside their household (74.3%, 77.0% and 89.2%, 90.5%). In addition, most patients and care partners reported monitoring for symptoms of COVID-19 (79.1%, 81.1%) and frequently

Table 2 – Synthesized findings from survey and interview results.

Theme	Survey	Interviews	Synthesized Finding
Theme 1: Navigating risk, coping with uncertainty	<p>Risk for contracting COVID-19 (%) Pt: no = 55, yes = 29, U/S = 16 CP: no = 50, yes = 31, U/S = 19</p> <p>Risk for COVID-19 adverse outcomes (%) Pt: no = 25, yes = 55, U/S = 20 CP: no = 24, yes = 47, U/S = 28</p> <p>Adoption of risk-mitigating behaviors (%) Physical distancing: Pt = 92, CP = 95 Mask wearing: Pt = 95, CP = 92 Limiting indoor contacts: Pt = 89, CP = 91 Limiting outdoor contacts: Pt = 74, CP = 77 Monitoring symptoms: Pt = 79, CP = 81</p>	<p>“[T]he general response that we’ve gotten [is he’s] not at high risk, or likely not at high risk. But we just don’t know enough about this to really know that. So, I’m more concerned about that, and I’m very conservative in terms of keeping safe and not being around others.” - CP</p> <p>“I was working, and I had my health coverage, and I was seeing a cardiologist on a regular basis. And then when COVID hit I didn’t go back to work because of fear that something would happen . . . I said to myself, ‘If I get this, I don’t know how my body will react to it.’” - Pt</p>	<p>Uncertainty associated with the lack of available guidance from reliable sources on whether having or being at risk for AD constitutes a risk condition for COVID-19. Individuals in the AD community have widely adopted protective behaviors that are in line with public health guidance on mitigating risk for COVID-19. These behaviors serve to reduce actual/potential risk and serve as a mechanism for allaying the anxiety produced by lack of clear guidance on risk status. Individuals in the AD community report that before the COVID-19 pandemic, the environment in which they and their family members navigated and accessed care was marked by a high level of complexity. The COVID-19 pandemic presents new challenges and barriers to accessing care, resulting in increased burdens on individuals to navigate this complex environment in order to maintain their aortic health.</p>
Theme 2: Increased burden and complexity of care	<p>Clinic appointments cancelled (%) Patients: 67 Care partners: 72</p> <p>Surgery cancelled (%) Patients: 43 Care partners: 50</p> <p>Emergency care avoided (%) Patients: 40 Care partners: 15</p> <p>Worry about continued care access (%) Ongoing needs: Pt = 37, CP = 42 Surgery: Pt = 22, CP = 26</p>	<p>“So, I didn’t get to do my test that day, and then it was this whole fiasco of getting clearance and all of this . . . which just increases my anxiety. I keep reminding myself ‘If my dissection extended . . . we’re doing what they would do to medically manage it anyway.’” - Pt</p> <p>“I did go to the ER . . . I ended up going home . . . [Y]ou’re thinking ‘I don’t really want to walk into an ER if I don’t absolutely have to.’ And I couldn’t have somebody there with me, that was the other thing . . . so if I got admitted I was going to be there by myself. All those things were just added on to the usual thought process of ‘Do I really want to waste my time with going to the ER if it’s going to be absolutely nothing?’” - Pt</p>	<p>Telehealth played a key role in the AD community maintaining access to care during COVID-19-related care disruptions. Access to telehealth also reduced some of the unique geographic, economic, and time-related barriers at-risk/patients with AD face under nonpandemic conditions. Specific circumstance may call for in-person care, such as at times of complex treatment decision making.</p>
Theme 3: Reducing barriers to care with telehealth	<p>Telehealth Satisfaction Scale (%) Felt comfortable with TH: Pt = 75, CP = 88</p> <p>Could not see provider without TH: Pt = 63, CP = 58</p> <p>TH easier than in-person: Pt = 55, CP = 46</p> <p>Better results with TH: Pt = 12, CP = 4</p> <p>Prefer in-person: Pt = 72, CP = 75</p>	<p>“The telehealth appointments this year were a reprieve from some of the traveling. . . They are really super helpful, even if it’s a local doctor, when you have a kid who has all of these doctors . . . I think that COVID pushed the health care system into doing it, and I hope that it sticks around a bit.” - CP</p> <p>“It seemed harder to have the real conversation about ‘are you going to do this surgery, or not?’ We went in person [to make] that decision . . . so, it was good, but I felt that telemedicine also had its limitations.” - CP</p>	<p>Telehealth played a key role in the AD community maintaining access to care during COVID-19-related care disruptions. Access to telehealth also reduced some of the unique geographic, economic, and time-related barriers at-risk/patients with AD face under nonpandemic conditions. Specific circumstance may call for in-person care, such as at times of complex treatment decision making.</p>

Abbreviations: AD, aortic dissection; CP, care partner; ER, emergency room; Pt, patient; TH, telehealth; U/S, unsure.

cleaning/disinfecting their homes (57.7%, 78.4%). Only 1.2% and 2.7% of patients and care partners, respectively, reported adhering to none of the recommended protective behaviors.

Interview participants noted that evaluating the level of risk for COVID-19 conferred by aortic health status was challenging at best. Personal risk assessments were often made in the absence of reliable information and resulted in a high degree of uncertainty. Many participants expressed frustration at the lack of consistent information from reliable and trusted resources. Even when such information was available participants noted that it was sometimes contradictory, further complicating their ability to accurately assess their risk. In the atmosphere of uncertainty created by lack of consistent risk information, even guidance given by trusted medical professionals was seen as potentially incorrect, unreliable, or subject to change.

Participants noted that their uncertainty about risk directly influenced their decision making about risk mitigation strategies. Among participants, such strategies occurred along a spectrum. On one end, individuals reported strict adherence to basic public health guidance; on the other end, participants reported dramatic changes in lifestyle, sometimes at great potential cost to themselves and their families. Participants also noted that in addition to reducing actual or perceived risk for COVID-19, these strategies served to reduce their anxieties about whether AD contributed to COVID-19 risk.

The AD community lacked clear guidance about whether their aortic health status contributed to COVID-19 risk. As a result, adopting protective behaviors was both a risk- and anxiety-reduction strategy in this context. Synthesized analysis of quantitative and qualitative results provided a nuanced picture of how individuals perceived their level of risk and coped with the uncertainty associated with the lack of available guidance from reliable sources on whether having or being at risk for AD constitutes a risk condition for COVID-19. Perceptions of risk varied widely across the sample, in both survey respondents and interview participants. Theme 1 also revealed that people in the AD community widely adopted protective behaviors that are in line with public health guidance on mitigating risk for COVID-19, and that these behaviors served to reduce actual risk of potential exposure to the virus while also serving as a mechanism for allaying the anxiety produced by lack of clear guidance on risk status.

### 3.2. Theme 2: Increased burden and complexity of care

A significant proportion of survey respondents reported disruptions in care related to their aortic health since March 2020. These disruptions took the form of cancelled clinic appointments and scheduled surgery, and decreased access to emergency care. A total of 287 patients and 53 care partners reported having at least one aortic health-related clinic appointment scheduled since March 2020. Of those, 41.5% of patients and 50.9% of care partners had clinic appointments cancelled or rescheduled. Of the 30 patients and 10 care partners who reported scheduled aortic surgery, 43.3% and 50% reported cancellations, respectively. For both clinic appointments and surgery, most cancellations were initiated by the health care provider or clinic. The reason most fre-

quently cited for provider-initiated cancellations was cancellation of all nonemergent care (patients 86.5%, care partners 85.0%). In instances when patients or care partners initiated the cancellation, worry about contracting COVID-19 was the most frequently cited reason (patients 64.6%, care partners 87.5%).

Regarding access to necessary ongoing care, monitoring, and medication, 36.8% of patients and 41.9% of care partners reported worrying about care disruptions, whether or not they had experienced any actual disruptions to date. Of these respondents, 24.8% of patients and 41.9% of care partners reported feeling very or extremely worried. Regarding access to necessary surgery, 21.9% of patients and 25.7% of care partners reported worry about care disruptions. Of these respondents, 35.2% of patients and 68.4% of care partners reported feeling very or extremely worried.

The survey also asked respondents whether, since March 2020, they had experienced any aortic health symptoms that required emergency care: 59 patients and 13 care partners reported they had. Although most of those respondents reported they did seek emergency care, a small-yet-significant number reported choosing not to go to the emergency room or urgent care center to seek care (39.6% of patients, 15.4% of care partners). The reason most commonly cited by those who did not seek emergency care was worry about contracting COVID-19 (71.4% of patients, 100% of care partners). One patient reported experiencing “continued heart pains” as a consequence of not seeking emergency care; the remainder of patient and care partner respondents reported no consequences.

Interview participants reported that before the COVID-19 pandemic, the environment in which they and their family members navigated and accessed care was marked by a high level of complexity. Living with or at risk for AD necessitates managing care across multiple care settings, including specialists, surgeons, and general practitioners, as well as complexities related to daily management of health. When asked to reflect on how the COVID-19 pandemic had impacted their care related to aortic health, interview participants reported increased complexity related to clinics closing, loss of direct access to their care providers, and confusion about the implications of COVID-19 mitigation on appropriate care navigation. Interview participants also described the tensions they faced when deciding how and when to access care. Need for ongoing monitoring and other care was weighed against the backdrop of risk for COVID-19 exposure, inability for care partners to accompany family members during care, and the increased scheduling and other logistical difficulties imposed by the pandemic. For example, participants noted how difficult scheduling necessary monitoring appointments had become during the pandemic, citing cancellations of nonurgent appointments and lack of clarity about when appointments would be available. They also described the emotional toll of uncertainty about their aortic health status caused by delayed access to these appointments. Tensions were heightened for participants who developed symptoms they thought required emergency care. In one such instance a participant described that COVID-19-related risk considerations, coupled with indecision about the seriousness of their symptoms, led them to leave the emergency department before being seen. This and other experiences described by participants exemplify the

increased complexity of accessing necessary care during the COVID-19 pandemic.

It is also important to note that some interview participants reported experiencing no disruptions or increased complexity in accessing aortic health-related care. This occurred most often when the person's regular care schedule happened annually or semi-annually and scheduled appointments did not coincide with the early months of the pandemic, and they had not required any additional unplanned care during that time.

For people living with or at risk for AD, the COVID-19 pandemic increased the complexity and burden of navigating an already complex health care environment in order to maintain their aortic health. Synthesis of survey and interview results demonstrate significant disruptions to accessing care related to aortic health during the COVID-19 pandemic; these results provide rich context about how those disruptions manifested, highlighting how decreased and delayed access to care contributed to patient insecurity and anxiety about aortic health status.

### 3.3. Theme 3: Reducing barriers to care with telehealth

Within our survey sample, 123 patients (29.6%) and 24 care partners (32.4%) reported having at least one telehealth appointment since March 2020. Most respondents rated these experiences highly; 74.8% of patients and 87.5% of care partners reported feeling comfortable with their telehealth appointment, 63.4% of patients and 58.3% of care partners reported they would not have been able to see their provider without a telehealth appointment, and 54.5% of patients and 45.9% of care partners reported that having a telehealth appointment was easier than seeing their provider in person. However, only 12.2% of patients and 4.2% of care partners felt they received better results by having a telehealth appointment, and a large majority (71.5% of patients and 75.0% of care partners) reported a preference for seeing their provider in person.

Interview participants' experiences with telehealth reflected the survey findings that support for telehealth was generally high; many participants noted that telehealth played an important role in facilitating continuity of care in the face of disruptions to or concerns about in-person care. Participants also noted that access to telehealth reduced some of the unique barriers people in the AD community face in accessing comprehensive care regardless of the conditions imposed by the COVID-19 pandemic. Interview participants reported that they were under the care of multiple clinicians, sometimes including rare disease specialists in cities and/or states outside their home area. Access to these clinicians often necessitated long distance travel. Even when care was found locally, participants described that maintaining care with multiple providers (eg, cardiologists, vascular specialists, geneticists, surgeons, and primary care practitioners) was time consuming and burdensome. The ability to access care via telehealth during the COVID-19 pandemic dramatically decreased these burdens for many participants.

Although participants articulated the benefits of telehealth care, they noted specific circumstances in which in-person

care was preferred or considered most appropriate. Many participants felt that certain types of medical appointments required "hands on" care, or in-person discussion. Examples included imaging follow-up appointments, establishing care with a new provider, and discussions about complex treatment decisions (eg, presurgical consults).

Telehealth was a critical component of how the AD community navigated access to care during the COVID-19 pandemic, but not all telehealth was perceived as effective care. Synthesis of survey and interview results illustrated that acceptance of telehealth among patients and care partners in the AD community was high but carried important caveats. Survey results revealed those who had at least one telehealth appointment since March 2020 had generally positive experiences; interviews revealed that while support for telehealth was high, respondents desired flexibility in which appointments to attend via telehealth based on their personal preferences and needs. These synthesized findings indicate an ongoing role for telehealth in providing personalized, accessible care to the AD community.

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## 4. Discussion

Our synthesized findings reveal areas for future research, policy work, and practice development (Table 3) that are critical for supporting the wellbeing of the AD community. The time period represented by this project, between March and October 2020, was characterized by conflicting, inconsistent, or absent guidance about whether aortic health status confers risk for acquiring or having complications of COVID-19 [17,18]. Conflicting reports early in the pandemic implied alternately that medications commonly taken to manage AD and the conditions that place individuals at risk for AD might either increase or pose moderate risk for poor outcomes of COVID-19 [19–21]. Although the Centers for Disease Control and Prevention established guidance on common health conditions that contribute to increased COVID-related risk, including "heart conditions," information specific to aortopathies, including AD, was not included in the forthcoming guidance [22]. In part to address this information gap, in March 2020, The Marfan Foundation issued a professional advisory statement based on expert opinion about the role of genetic aortic disorders in relation to risk for COVID-19 [23]. This statement noted that individuals with and at risk for AD are not considered at high risk for COVID-19 unless their disease also manifests one of the known risk conditions identified by Centers for Disease Control and Prevention (eg, high blood pressure, heart failure, and chronic obstructive pulmonary disease), or impacts other body systems outside the aorta.

Yet patients and care partners included in our project endeavoring to understand personal risk felt they lacked the necessary information to help them effectively navigate risk in their day-to-day lives. Taken together, the available information from all sources was seen as preliminary, incomplete, and conflicting, and it did not provide the evidence needed to understand how aortic health status contributes to risk for COVID-19. Because perception of risk for COVID-19 has been demonstrated to relate to adoption of recommended protective behaviors, accurate, and timely information about risk



**Table 3 – Implications for policy, practice, and research by theme.**

Theme	Recommendations for policy, practice, and research
Theme 1: Navigating risk, coping with uncertainty	<p>Improve communication about what is known and what remains unknown about aortic health status risk for COVID-19.</p> <p>Develop guidance specific to rare disease risk for COVID-19, including for AD and conditions that predispose for AD.</p> <p>Encourage funding agencies to direct funds to study the impacts of COVID-19 on people with rare disease and AD.</p> <p>Add COVID-19-related data to current and future research projects on aortopathy/AD to build datasets that can contribute to knowledge generation.</p>
Theme 2: Increased burden and complexity of care	<p>Develop safety-net strategies to ensure continuity of care for clinically fragile patients with AD during times of uncertainty or disruption.</p> <p>Implement strategies to maintain communications/relationships between patients and their care providers when facing delays in appointments/procedures for all patients with AD regardless of clinical status.</p> <p>Identify and address the psychological impacts of delayed care on patients and prioritize contact with those who may be more susceptible to anxiety.</p>
Theme 3: Reducing barriers to care with telehealth	<p>Develop federal and state policy that will ensure continued access to telehealth for aortic health–related care.</p> <p>Increase access to telehealth for aortic health as a strategy to reduce geographic, economic, and time-related barriers to care.</p> <p>Address the remaining logistical challenges (eg, provider licensure and billing) that are currently inherent to the wide-scale provision of telehealth services.</p> <p>Assess what models for telehealth produce improved outcomes for aortic health, with a focus on patient-centered models that consider individual contexts and preferences for in-person versus telehealth care.</p>

Abbreviation: AD, aortic dissection.

status is critical to an individual's ability to make informed decisions that may have serious consequences for their or their family member's health [24–26]. Moving forward, it is critical to more fully understand whether and how aortic health status specifically contributes to that risk, as long as COVID-19 remains a health threat. This will require research addressing to what degree aortic health status is implicated in risk for COVID-19.

It is also important to ensure that the AD community is able to maintain access to critical health care services during times of uncertainty. Regular monitoring and ongoing preventive care are key to maintaining health for this population; aortic health crises can arise without patients experiencing outward signs or symptoms until the event occurs [27]. Patients rely on consistent monitoring to provide reassurance. Our results indicate that while participants in our survey and interviews did not have significant aortic health consequences of delayed or deferred care during the period under investigation, they nonetheless were significantly affected by disruptions in care. Those impacts were felt in increased burdens on individuals to maintain continuity of care, while simultaneously navigating an increasingly complex health care environment in which the availability of care was often limited. Even when care was available, the emotional toll of prolonged intervals between monitoring or preventive care appointments was felt by many. When care is not readily available, or appointments must be delayed, individuals would benefit from continued contact with their providers and open communication about their concerns. We recommend proactive planning for future pandemic-related care disruptions to develop safety-net strategies that can improve care continuity in those circumstances. This should include identifying medically and emotionally vulnerable individuals in order

to plan appropriate communication strategies when care is disrupted.

Finally, our results demonstrate that a key to ensuring continuity of care for the AD community lies in the continuation and expansion of appropriate telehealth services. Telehealth has provided an important safety net for many patients with AD to continue to receive care in a low-risk setting during the COVID-19 pandemic. Federal policy changes enabled by the declaration of a public health emergency due to the COVID-19 pandemic allowed for the rapid expansion of telehealth services across the United States [28]. Our analysis highlights the “unintended consequence” of the expansion of telehealth services resulting in substantially decreased barriers to care for individuals in the AD community who must often travel long distances to access specialist care or who were previously unable to access that care due to financial or geographical constraints. Yet these policy changes are temporary and intended to sunset when the COVID-19 public health emergency declaration expires [28]. Continued access to telehealth services beyond the COVID-19 pandemic may contribute significantly to improved care access and health outcomes for people living with and at risk for AD. It should be noted that any expansion of telehealth services must also address the fact that access is not equitably distributed across the population. Additional infrastructure and other supports are needed to ensure that telehealth services do not replicate or deepen existing health-care inequities within the AD community.

#### 4.1. Limitations

This project represents the experiences of the AD community during the first few months of the COVID-19 pandemic. As such, our findings represent a snapshot in time. The 7 months

were unique during the pandemic in that they encompassed the initial wave of COVID-19 cases in the United States, as well as the initial public health response to the crisis [29]. It is possible that the AD community may have reported different experiences had we conducted this project at a different time point in the pandemic, for example after the beginning of vaccine distribution in December 2020, or during the rapid rise in Delta variant cases in summer and fall of 2021. Repeated surveys or interviews would add significantly to our understanding of how the ongoing COVID-19 pandemic continues to affect the AD community. Because our survey distribution method was entirely online via a publicly available REDCap survey link we are unable to calculate a survey response rate. In addition, distribution relied heavily on the social media and e-mail lists of AD Collaborative collaborating organizations (eg, Marfan Foundation). Because of this, our survey sample included higher representation of patients with syndromic conditions than is found in the AD population more generally. Other demographic characteristics (eg, age and sex) of our sample may also not be proportional to that of the general AD population. For example, our survey sample includes more women and younger individuals than previous work indicates may be represented among those with AD [1,30]. Purposive sampling among interview participants was used to ensure adequate representation across diagnostic and demographic characteristics of participants, but survey results may reflect a bias toward the experiences of groups with higher representation among respondents.

## 5. Conclusions

The findings from this mixed methods project provide important insight into the experiences of people with or at risk for AD during the COVID-19 pandemic. Our synthesized analysis of quantitative and qualitative results sheds light on the complexities of living with or at risk for AD at a time characterized by uncertainty, worry, and lack of consistent guidance. Our analysis also reveals how complex care access issues generated by the pandemic impacted the AD community. The findings reported here also shed light on the strategies, including telehealth, that were effective in helping alleviate some of the burden associated with maintaining continuity of care in a population for whom consistent and accessible care is critical to maintaining health. This work also highlights the importance of key policy, practice, and research areas that have the potential to significantly contribute to improved care and health outcomes for people living with or at risk for AD during and beyond the COVID-19 pandemic.

## Conflicts of Interest

Kim Eagle receives support from the Marfan Foundation and WL Gore. No other authors have competing interests to declare.

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1053/j.semvascsurg.2022.02.006.

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