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Review article

The mental health impact of aortic dissection

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ABSTRACT

Although the topics of surgical techniques and medical therapies have been widely studied in aortic dissection (AD), studies examining the short- and long-term impact of this event on mental health are largely lacking. Many of the studies have used the 36-Item Short Form Survey at variable time points after the event. However, AD as medical trauma has a complex impact on a person's identity. Its implications for emotional, mental, social, existential, and self-concept could be explored more robustly. This topic was identified as a topic of interest by the AD Collaborative. The AD Collaborative Mental Health Working Group was formed and performed a landscape review to summarize current literature surrounding quality of life research in those who have experienced AD, identify gaps in knowledge, and to outline future research questions.

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1. Introduction

The Aortic Dissection (AD) Collaborative was established in late 2019 to determine the research priorities of the patients living with AD [1,2]. As a consequence of this work, the topic of mental health was identified by the stakeholders as topic of research interest. The AD Collaborative Mental Health Work-

ing Group was established to specifically focus on this topic. Numerous studies have examined the benefits of medical and surgical interventions in improving survival outcomes after AD, including optimization of surgical techniques, cerebrovascular protection, and biomarkers. Studies often do not consider the psychosocial elements or the patient's mental health after diagnosis or subsequent treatment. A preliminary literature search for AD treatment will yield thousands of citations; in contrast, a literature search for mental health outcomes in patients with AD will yield just a few studies. And yet, when trying to improve medical care for patients impacted

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by AD, mental health and quality of life (QoL) research is vital. When questioned, patients have desired more information about how AD affects daily living, functional ability, and QoL [3].

In 1948, the World Health Organization (WHO) defined *health* as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [4]. Determinants of mental health can be social, psychological, and biological. The WHO states that mental health encompasses “subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational dependence and recognition of the ability to realize one’s intellectual and emotional potential” [5]. The WHO goes on to define *quality of life* as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [5]. Health-related quality of life (HRQoL) refers to a subcategory of QoL specific to health. In a study discussing these QoL-related definitions, Post et al [6] stated that “health, perceived health, health status, HRQoL, and QoL are treated as synonymous by many researchers and clinicians.” Given the breadth, complexity and individualized factors that can affect QoL, it can be assessed from different perspectives, including subjective reporting, objective reports, and function-based reports [6].

Patients experiencing an acute AD (or those learning that they have a condition that places them at risk for AD) deal with short- and long-term physical and emotional sequelae that may be considered medical trauma. *Medical trauma* is defined as a set of psychological and physiological responses to pain, injury, serious illness, medical procedures, and frightening treatment experiences [7]. It can be viewed as an acute onset of a disrupted physiological system in which the ongoing threat is internal (ie, AD) and may be long term or permanent [8]. Medical trauma can result in clinical psychiatric conditions, such as anxiety, depression, and post-traumatic stress disorder (PTSD) [7]. The DSM-5 (*Diagnostic and Statistical Manual of Mental Health Disorders, Fifth Edition*) considers PTSD as the exposure (either experienced, witnessed, or experienced by close individuals) to traumatic events resulting in various symptoms and cognitive changes appearing after and due to the event [9].

PTSD due to medical trauma is not uncommon. In the United States, it has been reported that 7% of all PTSD cases are illness-induced [10]. Although individual studies offer prevalence estimates for medically induced PTSD within cardiac patients that vary widely, from 0% to >30%, large observational studies and meta-analytic estimates have returned fairly consistent estimates of approximately 12%–25% [11–13]. In addition, PTSD is also experienced in 20%–30% of patients with critical illness who are admitted to the intensive care unit and in 20% of major-surgery postoperative patients [14,15].

In addition to the acute event, the likelihood of additional surgical interventions, the need for continued monitoring, and the psychological burden of figuring out a “new normal” for these patients can be emotionally burdensome [16]. Studies on QoL in AD have often lacked nuance into the complexities of factors that influence coping and outcomes. In line with patient-centered research, the purpose of this landscape review was to evaluate the medical trauma of AD, ex-

amine its impact on mental health and QoL, and to propose directions and questions for future patient-centered AD research.

2. Methods

A review of the literature concerning the mental health impacts of AD was conducted using PubMed, with no restrictions placed on country or publication date. Search was performed up to publications as of June 2021. Medical Subject Headings (MeSH) search terms included the following: (AD) AND (mental health, Quality of Life (QoL), Post-traumatic stress disorder (PTSD), anxiety, depression, grief, OR fear. Comparisons with other topics in cardiac literature were conducted by less comprehensive searches of these topics AND (cardiac). Because care for patients with AD is both acute and chronic and requires a multidisciplinary team, we postulated that oncology care would be a relevant medical discipline to examine for mental health guidelines to compare and contrast with services found in cardiology. Relevant oncology literature was obtained through a Google search of Oncology guidelines AND mental health.

Two main inclusion criteria were used: the article was written in the English language, and the study or review focused on mental health topics related to aortic disease (aneurysm or dissection). We excluded abstract-only publications.

Information regarding study methods (qualitative, review, survey, or intervention), study population, sample size, survey instrument, and brief summary of results were abstracted from the articles. We also noted conclusions drawn by the investigators and that stated “future areas of research.”

3. Results

Nineteen articles that met inclusion criteria were identified and reviewed. Some articles also included patients undergoing prophylactic aortic root repair and one article included focus group responses of patients, caregivers, and health care professionals. One meta-analysis and subsequent commentary reviewed 30 studies (4,747 patients) who underwent a variety of aortic operations (eg, thoracic, descending, abdominal, and both AD and prophylactic operative repairs) [17,18]. More than one-half of the studies used the 36-Item Short Form Survey (SF-36) or SF-12. See Table 1 for a brief description of studies.

3.1. Impact of AD medical trauma on mental health

3.1.1. Quality of life

An overwhelming majority of studies evaluating emotional well-being demonstrate an impact on QoL in patients with AD. There are mental health concerns at different time points of AD, including from diagnosis to hospital discharge to years post event. Focused interviews of patients experiencing medical trauma from AD have identified patients’ fears and concerns. First, the diagnosis of AD was a frightening time raising concerns for one’s mortality. Jönsson et al [19] found patients asking, “Am I going to die now?”—which was an existential

Table 1 – Review of mental health studies in patients with aortic dissections.

First author, year	Study population	Sample size (n)	Study method or survey instrument	Brief summary of results
Olsson, 1999 [20]	AoSurg (AD or AoAn)	76	SF-36	Mental health, vitality, social functioning, general health, and physical functioning were significantly lower than in the normal population. Emotional and physical role functioning were substantially lower than the norm. Bodily pain reported was no different from that of the normal population. Patients' self-experienced QoL either improved or was maintained by surgery, with the majority reporting improved health perception after surgery.
Winnerkvist, 2006 [55]	Type B AD	53	SWED-QUAL	Patients with AD, compared with normal male counterparts, scored lower in an index that assessed general health. Female patients scored lower on general health, physical functioning, satisfaction with physical functioning, and emotional role functioning than normal female counterparts.
Dick, 2010 [35]	Desc Ao TEVAR (type B AD or AoAn)	58	SF-36, HADS	QoL was similar in a mid-term analysis of patients who underwent elective versus emergent AD surgery; however, QoL was certainly less in both cohorts compared with the standard population.
Olsson, 2013 [57]	TAAD	178	SF-36	A significantly reduced HRQoL compared with a sex- and age-matched reference group from the general population was evident in three (PF, RP, and GH) out of eight SF-36 domains and in the PCS, but not in the MCS.
Olsson, 2013 [58]	Proximal AoSurg (AD or AoAn)	207	SF-36	HRQoL in patients who underwent procedures involving the proximal aorta was overall near-normal with no significant differences between procedure types (eg, AD v AoAn).
Chaddha, 2015 [30]	Type A/B AD	82	Qualitative survey	This study demonstrated increased inactivity in patients after AD as a result of fear. There was also an increase in new-onset depression and anxiety (32% and 32%). More than 50% of patients who experienced inactivity reported new-onset depression after AD. One-third of patients felt AD limited their sexual activity.
Jussli-Melchers, 2017 [59]	Type A AD	242	SF-36	Psychological well-being was comparable in both young and old Type A survivors. However, the QoL scores were lower compared with the general, age-matched population in Germany especially with regard to the terms <i>pain score</i> and <i>social functioning</i> .
Adam, 2018 [31]	Type A AD	210	SF-12, PDS, PTSS-14	AD was associated with self-reported depression and anxiety in 25.8% and 24.8% of patients. In addition, AD has negatively affected patients' sexual activity. This study also demonstrated PTSD in patients with AD.
Acosta, 2019 [3]	AD or caregiver	75	JLA process	A list of 24 research uncertainties for AD was filtered to the top 10: QoL ranked third, with rehab after AD at #7, psychological consequences of AD at #8. Uncertainties particularly affected the areas representing professional activities, subjective assessment of general health, life activity, and emotional background.
Kamenskaya, 2019 [23]	Type A AD	82 (73 for SF-36)	SF-36	A positive dynamic was observed for almost all parameters of the HRQoL, including two summary measures (PCS and MCS), 1 year after prosthetics of the ascending aorta and the aortic arch, except with respect to the scales PF, MH, and GH. Important data are the low HRQoL then, at baseline, which would represent the AD group living with chronic AD. The preoperative values of HRQoL including two summary measures were ≤ 43 points for most SF-36 scales except PF, SF and MH, which indicates a low level HRQoL.
Pasady, 2020 [32]	Type A AD	129	PC-PTSD, IRAD lifestyle survey	This study demonstrated PTSD in patients with AD; 23% of patients screened positive for PTSD, with the highest symptom being "constantly on guard, watchful or easily startled" approximately a median of 6.8 y after dissection. Most patients had at least one positive PTSD symptom. Patients who experienced postoperative complications were more likely to have a positive PTSD screening result.
Bi, 2020 [34]	Type B AD	53	MOS, SF-36	This study demonstrated that, except for role emotion, vitality, and mental health, all remaining domains were significantly improved after TEVAR compared with before TEVAR.
Sbarouni, 2021 [22]	Type A AD	28	SF-36	This study evaluated physical composite score (PCS) and mental composite scores (MCS) in patients who underwent surgery for AD at 1, 5, and 10 years. PCS was higher at 5 years than at 1 and 10 years. Mental composite scores at both 5 and 10 years were significantly higher than at 1 year, implying delayed mental recovery following surgery.
Chen, 2020 [60]	Type A AD	214	PCL-C, SSRS, HADS, CD-RISC	PTSD symptoms were found in 21.5% of the respondents including 22.1% of the male patients and 20.0% of the female patients.

(continued on next page)

Table 1 (continued)

First author, year	Study population	Sample size (n)	Study method or survey instrument	Brief summary of results
Jönsson, 2020 [19]	Type A/B AD	10	Focus group	Four qualitative themes were identified: "Am I going to die now?" (existential turning point); "compromised integrity during admission-experiences of hospitalization" (lack of integrity of self, lack freedom, no control of personal hygiene); "signals from my body; a new awareness of my body after discharge" (exhaustion/weakness led to feelings of uncertainty and constant awareness of body, pain, BP); "what can I do now?" (uncertainties about level of exercise and daily living (lifting))
Meinlschmidt, 2020 [29]	AD, caregiver, or health professional	42	Self-developed survey	Participants indicated areas that they believed needed psychosocial attention after AD, more than half the respondents selected "changes in everyday life," "anxiety," "uncertainty," "tension/stress," and "trust in the body." Other issues mentioned in the free response category were "insurance issues" and "pension issues." The most common psychosocial interventions preferred were family/relative therapy and anxiety treatment.
St Pierre, 2021 [21]	Type A or aortic valve repair	195	SF-36	This study demonstrated decreases in all 8 domains of the SF-36 survey post-surgery in patients with TAAD; however, there were no significant decreases seen in the mental health domain.
Luo, 2021 [54]	Type A AD surgery survivors >6 months	175	IIEF-5, Q-LES-Q, SF-12, QIDS-SR, BDI-II	This study reported that sexual dysfunction after AAD surgery is 38.9%, with higher prevalence in the elderly and lower in the young.
Lin, 2021 [33]	type A/B AD	224	CD-RISC, HADS, PCL-C	21.4% of patients tested positive for PTSD. The symptoms of PTSD among patients with AAAD in this study were mainly re-experience and increased alertness.
Syndrome-specific studies				
Velvin, 2016 [24]	MFS	73	SWLS, FSS, Nordic chronic pain scale	This study demonstrated increased distress and decreased SWL score in patients with AD
Goldfinger, 2017 [61]	MFS	389	SF-36	This study demonstrated a decrease in PCS, but within 1 SD of mean. Notably, factors related to health and MFS severity did not correlate with better or worse QoL.
Benke, 2017 [27]	MFS	45	STAI, BDI (SF), Berne questionnaire of subjective well-being (SWLS-H)	Increased STAI and anxiety in patients who underwent urgent/emergency surgery for acute AD than in MFS patients who underwent prophylactic surgery or medical management and compared to general population
Bons, 2019 [28]	SMAD3 (LDS3)	28	SF-36, HADS, Rotterdam disease specific questionnaire	Patients reported concerns about early mortality, future health, requiring future surgery suture, and the hereditary nature of the disease. Patients with SMAD3 reported a lower quality of life, higher depression, and lower physical role functioning.
Thijssen, 2020 [56]	HTAD	142	SF-36, HADS, NCSI	Patients with HTAD scored significantly lower on the SF-36 than the general population in general health and vitality domains. Female patients also score significantly lower in the physical functioning and role physical domains.

Abbreviations: AAAD, acute type A aortic dissection; AD, aortic dissection; AoAn, aortic aneurysm; AoSurg, aortic surgery; BDI-II, Beck Depression Inventory-Second Edition; CD-RISC, Connor-Davidson Resilience Scale; Desc Ao, descending aorta; FSS, Fatigue Severity Scale; HADS, Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life; HTAD, heritable thoracic aortic disease; IIEF-5, International Index of Erectile Function; IRAD, International Registry of Acute Aortic Dissection; JLA process, James Lind Alliance process; LDS3, Loeys-Dietz syndrome type 3; MFS, Marfan syndrome; MOS, Medical Outcomes Support Survey; NCSI, Nijmegen Clinical Screening Instrument; PC-PTSD, Primary Care Post Traumatic Stress Disorder; PCL-C, Post-traumatic Stress Disorder Checklist-Civilian version; PDS, Post-traumatic Stress Diagnostic Scale; PTSD, post-traumatic stress disorder; PTSS-14, Post-traumatic Stress Symptoms-14; Q-LES-Q, Quality of Life Enjoyment and Satisfaction Questionnaire; QIDS-SR, Quick Inventory of Depressive Symptomatology; SF-12, 12-Item Short Form Survey; SF-36, 36-Item Short-Form Survey. The SF-36 measures eight scales, physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH). There are two distinct concepts measured by the SF-36, a physical dimension, represented by the Physical Component Summary (PCS), and a mental dimension, represented by the Mental Component Summary (MCS). All scales do contribute in different proportions to the scoring of both PCS and MCS measures; SSRS, Social Support Rating Scale; STAI, State-Trait Anxiety Inventory; SWED-QUAL, Swedish Health-Related Quality of Life Survey; SWLS, Satisfaction With Life Scale; TAAD, thoracic aortic aneurysm or dissection; TEVAR, thoracic endovascular aortic repair.

turning point. When a physical threat to existence occurs, patients wrestle with the existential themes of death, freedom, isolation, and the meaning of life. Next, the hospitalization can be traumatizing, specifically because there is decreased freedom and personal hygiene may be compromised. On discharge from the hospital, there was heightened awareness of one's body, specifically symptoms that may reflect a pending adverse event. There were significant uncertainties about level of exercise and weight-lifting as well as sexual activity [19].

When compared with the general population of patients, patients undergoing operative repair for thoracic aortic aneurysm, dissection, or rupture experience worse QoL. Mental health, vitality, social functioning, general health, and physical functioning were significantly lower in this patient population (median follow-up time of 26 months) than in the general population in a review by Olsson and Thelin [20].

Typically, AD happens in a healthier population than in patients with chronic illness, such as those requiring aortic valve repair. A study comparing patients with chronic illness requiring aortic valve replacement versus patients with AD showed that QoL in patients who underwent sternotomy for aortic valve repair improved [21]. In contrast, patients who underwent sternotomy for repair of acute type A AD reported worse QoL. The rationale for this phenomenon was that patients undergoing aortic valve repair preoperatively had worse QoL (such as dyspnea on exertion) and experienced noticeable improvements in functional status after surgery, whereas AD was diagnosed in otherwise initially healthy patients who subsequently experienced a life-altering event. The study suggested a multidisciplinary approach (controlling hypertension, cardiac rehabilitation, cardiopulmonary fitness studies, physical exercise programs, and regular imaging surveillance of aorta) to help improve patients' QoL. The multiple points of support and education could empower patients looking to gain back their perceived loss of freedom and control after AD.

The impact on mental health of the disease appears to improve with time. In fact, Sbarouni et al [22] demonstrated in 28 patients with AD that there were improvements in the mental component score at 5 years and 10 years compared with patients 1 year post AD. Kamenskaya et al [23] reported improvement in most HRQoL domains after 1 year in their cohort of 73 patients with chronic Type A dissections who underwent ascending and arch repairs. However, in this study it is noted that there was an initially low level of HRQoL due to chronic dissection accompanied by severe pain syndrome. With the reduction of pain, there was significant improvement of HRQoL, including metrics specific to professional activities, energy potential, and emotional aspects.

3.1.2. QoL in patients with syndromic conditions

Most QoL studies have queried patients with the heritable thoracic aortic disease Marfan syndrome (MFS). In these studies, patients may not have had AD or significant aneurysmal disease and QoL may also be impacted by musculoskeletal disease (eg, scoliosis, flat feet, or joint laxity) affecting mobility and pain/fatigue and/or other nonvascular features, such as vision problems.

Patients with MFS experience decreased satisfaction with life compared with the general population, specifically as it relates to severe fatigue, AD, or psychological trauma [24]. Velvin

et al [25] performed a systematic review of patients with hereditary syndromes resulting in thoracic aortic aneurysm and dissection. Twelve of 17 studies showed decreased QoL in MFS, and few associations between HRQoL and symptoms were reported. Male sex, age, lower education, income, unemployed status, insurance hurdles, and little social support were variables associated with decreased QoL in MFS [25]. Worse QoL in patients with MFS compared with the general population was also confirmed in a large cohort study using the GenTAC (Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions) registry, which confirms the trend seen in smaller cohort analyses [26].

A study by a group from Hungary evaluated anxiety in 45 patients with MFS (three subgroups: acute/emergent surgery for AD, prophylactic aortic surgery, and nonsurgical cases) and compared them with the general population [27]. The study showed that patients with MFS and AD experienced more anxiety than the comparison groups. There was no statistically different anxiety between the general population and the MFS patients undergoing prophylactic surgery.

Finally, Bons et al [28] queried patients with SMAD3 variants (Loeys-Dietz syndrome type 3). This cohort raised concerns about dying at an early age, their future health, future surgery, and the heritability of their disease [28].

These results raise important questions about the impact of a genetic diagnosis on coping and QoL outcomes. Individuals may have access to support groups or educational resources that may bring comfort and good advice. Conversely, this access may raise fear because of the exposure to the wide spectrum of outcomes. Whether or not a person has a genetic diagnosis, when they get the diagnosis, additional considerations when studying QoL in AD include familial outcomes, the aggressiveness of the vascular disease predisposition, the additional multisystemic impact of disease on the person and familial implications.

3.1.3. Anxiety and depression

Patients have reported anxiety and depression after AD. Meinschmidt et al [29] obtained open responses from 27 patients with AD, 8 relatives of patients with AD, and 6 health care professionals who indicated areas that they believed needed psychosocial attention after AD. More than one-half of the respondents prioritized investigating psychosocial interventions for "changes in everyday life," "anxiety," "uncertainty," "tension/stress," and "trust in the body" [29]. Other challenges mentioned in the free response category were "insurance issues" and "pension issues." The most common psychosocial interventions preferred were family/relative therapy and anxiety treatment.

Chaddha et al [30] found that post-AD, new-onset depression and anxiety are common (32% and 32%). Adam et al [31] quantified patients' self-reported depression rate to be 25.8%.

3.1.4. PTSD

In acute type A AD, Pasadyn et al [32] found that 23% of patients had screened positive for PTSD. The highest symptom reported was being "constantly on guard," watchful, or easily startled at a median of 6.8 years after dissection. This

“hypervigilance” is hallmark of PTSD as described in DSM-5. Greater than 50% had at least one positive PTSD symptom, and those who experienced postoperative complications were more likely to have a positive PTSD screening result. Sixty-one percent of patients (76 of 125) reported that their dissection had affected their life in a negative way [32]. Patients who exercised (before or after AD) and were employed after dissection were less likely to screen positive for PTSD. In a Chinese cohort, PTSD was identified in 21.4% of patients [33]. These patients experienced adverse effects from medications as well as adverse physical and psychological events. The PTSD symptoms that patients experienced were reliving the experience and hyperawareness. The fact that acute surgical intervention in this population heightens patient anxiety has been confirmed in other studies. Benke et al [27], demonstrated higher than average anxiety in patients with MFS who underwent emergency aortic surgery compared with patients who underwent preventative prophylactic surgery or medical management. Interestingly, this trend of a worse impact of emergency surgery compared with elective surgery is not seen when minimally invasive approaches are used for AD. Two studies demonstrated that midterm QoL was comparable in patients who underwent emergent endovascular repair of type B AD versus with those who underwent elective repair [34,35].

3.1.5. Post-traumatic growth

Post-traumatic growth (PTG) is defined as experiencing positive changes after a negative event. Many factors affect a patient who goes on to experience or describe PTG, including personality, cognitive processing, psychological health, social support, and coping mechanisms [36]. The role of personality in how individuals experience PTG has been highlighted, with extraversion most likely to correlate with PTG [36].

Looking at PTG applied to other cardiac cohorts, Affleck et al [37] showed an 8-year decrease in morbidity in patients with a myocardial infarction who could cite benefits from their trauma by 7 weeks post event. Comparatively, in a systematic review to examine the correlates of PTG in patients who had an myocardial infarction, no conclusions could be drawn, as results showed an inconsistent pattern of association between PTG and any of the traits listed above [38]. Possible contributing factors, such as study quality, previous trauma, and cultural or methodological differences were highlighted. Ai et al [39] discussed that faith-based factors also play a predictive role for PTG in a cohort of nonemergency, nontransplant, and cardiac surgery patients. Lessons should be drawn from other cardiology specialties to help study design of PTG in AD.

4. Discussion

The cardiothoracic and vascular surgery literature investigating AD as medical trauma is sparse; only a few studies examine PTSD scales in AD, with rates of risk for or having PTSD ranging between 23%–31.5% [31,32]. There is more robust literature examining HRQoL outcomes in patients with AD with variable results. The relative paucity of investigation beyond SF-36 and the absence of interventional studies leaves us with many opportunities to explore the complex and

disease-specific mental health outcomes related to the medical trauma of AD.

4.1. Expanded application of mental health measurement tools

Literature review of mental health topics and outcomes within patients who have experienced AD does not appear to show replicable outcomes due to differences in qualitative versus quantitative research, measurement tools, and timing of when surveys are administered. Although known tools can be useful in evaluation of QoL, especially in a research context, they often cannot capture the nuances of issues and concerns that certain patient populations face.

The most commonly used survey to assess QoL in the AD population is the SF-36 [40,41]. The SF-36 assesses eight factors: general health, physical functioning, physical role functioning, emotional role functioning, social functioning, vitality, bodily pain, and mental health. Less commonly used are other QoL questionnaires, more focused surveys, or qualitative studies. Less comprehensive assessment can be performed by assessing factors contributing to QoL, such as the use of a chronic pain scale to assess pain levels or the Hospital Anxiety and Depression Scale to assess anxiety and depressive disorders [42].

Available tools may not fully encapsulate the complex disease-specific impact of an AD on an individual's coping and emotional outcomes. This is exemplified nicely by a meta-analysis by Jarral et al [17]. In fact, one of the main concerns with the studies in the review of Jarral et al was that there was no consistent time point in evaluating HRQoL. Furthermore, although two-thirds of the studies used the SF-36, the SF-36 is not health condition-specific and may have significant bias, especially because most studies are limited by the lack of preoperative data [18]. Important for future research into cardiac-specific mental health is the work of Jackson et al [43], which reports that development of a cardiac distress inventory is underway.

In order to achieve solid and comparable data, we have to agree on standards on reporting HRQoL after AD (or, potentially, a new aortopathy diagnosis). Given these inadequacies, we need to learn from and partner with experts in the mental health/PTSD landscape to determine study design, tools, and intervention to better capture what patients are reporting in qualitative studies. The goal is to empower health care providers to identify key clusters of psychological, emotional, and social concerns to address with a patient after AD. Application of more specific QoL and/or PTSD tools, as well as qualitative studies, will help us achieve better granularity into what provokes negative mental health outcomes after AD to help guide individualized intervention with the aim of moving patients to experience PTG.

Another challenge in studying AD as medical trauma is the lack of appreciation of how other non-disease-specific issues impact outcomes. These can include underlying mental health diagnoses, personality, past trauma, other life stressors, exercise and coping strategies, access to and uptake of therapies, cardiac rehabilitation, and support networks. The phasic nature of AD, ranging from acute event and urgent surgical intervention to long-term surveillance likely means

MENTAL HEALTH	<ul style="list-style-type: none"> • PTSD, anxiety, depression, grief, anger, uncertainty, fear, isolation
DEVELOPMENTAL LIFE STAGES	<ul style="list-style-type: none"> • Missed life events • Impact on family planning
RELATIONAL/ SOCIAL	<ul style="list-style-type: none"> • Familial impact (being a burden; fear about familial predisposition) • Social network impacts • Sexual activity and intimacy
OCCUPATIONAL/ FINANCIAL	<ul style="list-style-type: none"> • Insurance issues • Financial burden • Physical safety of job
PHYSICAL	<ul style="list-style-type: none"> • New awareness of body • Pain/fatigue • Physical limitations
SPIRITUAL/EXISTENTIAL	<ul style="list-style-type: none"> • Orientation of AD within one's faith beliefs • Mortality/threatened existence

Fig. 1 – Aortic dissection (AD) not only has a physical impact on the patient, but it can secondarily trigger stressors on other important life domains. PTSD, post-traumatic stress disorder.

that an individual's needs will evolve over time, necessitating an individualized therapeutic plan. We need to learn from both the patients and experienced healthcare providers to understand how the single medical event of AD impacts levels of stress in other life domains, potentially causing secondary crises that must be addressed in an overall wellness plan (Fig. 1).

There are examples of other cardiac-specific condition tools, such as the Myocardial Infarction Dimensional Assessment Scale, the Kansas City Cardiomyopathy Questionnaire and the Implanted Cardioverter Defibrillator Patient Concerns Questionnaire that address disease-specific concerns [43–45]. It may be that an AD distress tool needs eventually to be developed and validated. In the interim, application of a more diverse set of mental health evaluation tools could be more robustly applied.

4.2. Understanding current clinical experience

The European Society of Cardiology and the American College of Cardiology Foundation/American Heart Association guidelines regarding thoracic aortic disease do not specifically address mental health management in their respective 2014 and 2010 guidelines for aortic disease [46,47]. Currently, it is up to individual centers to determine whether or what mental health screening takes place, and to initiate mental health, cardiac rehabilitation, and support network referrals. Then, clinics must decide to have a standard protocol for a mental health care plan versus just offering options to

those perceived to be at risk for poorer QoL outcomes. Indeed, there could be clinics that have a very established, thoughtful, and successful pipeline that we can learn from. One research suggestion that may help in the development of guidelines is to understand the current practice in AD clinics in terms of assessment and referral patterns. Conversely, surveying patients about their experiences with assessments, referrals, and perceived needs is also important. This information could help drive short- and long-term protocols. Some ideas include implementation of screening tools in the electronic health record, automatic psychological assessment in the hospital post dissection, additional training for team members regarding mental health, implementing educational or self-reflection strategies that bring up mental health cues via text, email, handouts, or peer networking. There is not a one-size-fits-all approach to mental health in patients who have experienced AD, so over time, interventions will need to be individualized with multiple veering on and off points for patients needing more or less psychological support. Patients identify a “phasic nature” from acute event to short-term monitoring and possible surgical decision making to long-term management and then coping with familial recurrence. There is an incredible opportunity to create and appraise unique and creative assessment and intervention strategies in this population. An example can be drawn from Boutin-Foster [48], who asked patients with coronary artery disease “What are some of the changes that you have had to make in an effort to stay healthy?” and “What are some of the things that your family members, close friends, coworkers, and health care providers

have actually done that you found most helpful in making these changes?”

The current mental health resources provided to patients with a diagnosis of AD are limited. The best way to understand the disparity in resources is to observe the medical oncology literature and compare resources in that sector with resources for patients with AD. Cancer is a diagnosis that is life-threatening and chronic. In the National Comprehensive Cancer Network Guidelines for Distress Management, distress is considered to be a multifactorial unpleasant experience of a psychological (ie, emotional, behavioral, and cognitive), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms or its treatment [49]. In the field of oncology, a multidisciplinary approach uses mental health providers, health advocacy groups, psychiatrists, and geriatricians for a holistic approach to patients who have received a significant, life-threatening diagnosis. Much can be learned from this field and applied to patients with AD.

In addition, it is important to capture the experience of patients who have sought out or participated in therapy related to their AD. Searching for a therapist can be a challenge, and many financial and logistical barriers may exist. Finding a professional who has specialty experience with both acute and chronic illness and the fear and uncertainty that surrounds AD may also be a perceived barrier. Learning from the patients and professionals in these relationships can help the field develop resources that enable both members of the therapeutic relationship feel equipped and empowered.

4.3. Role of psychological support and support networks

There are virtually no studies on educational, therapeutic, or peer network interventions in AD. In the Common-Sense Model of Illness, patients use information from multiple sources to “make sense” of their health condition, and how they conceptualize the condition can strongly influence adaptation and coping responses [50]. Adaptive or maladaptive beliefs are associated with illness outcomes, including psychological well-being, HRQoL, and treatment adherence. This model was applied to patients who had an myocardial infarction with four 30-minute face-to-face sessions with a psychologist [51]. Patients who underwent targeted exploration of illness perception, on average, reported greater engagement in their physical activity and exercise, fewer contacts with their primary care provider, lower anxiety about returning to work, and better rates of return to work.

Addressing the use of the narrative medicine model, Fioretti et al [52] emphasized patient need for adequate time and space to share their subjective cardiac journey. Although there are likely time constraints that limit use of this model in the physician–patient relationship, the use of storytelling can be empowering and should be encouraged either within a peer network or therapeutic relationship.

Within the provision of psychological support and access and the experience with peer support networks, there is tremendous opportunity to try and learn best practices about interventions. These include timing, involvement of the health care team, involvement and/or impact on other family

members, partnering with advocacy groups, use of technology, and exercise. Each are addressed in the subsequent sections.

4.3.1. Timing?

When is it optimal to apply assessment and intervention and at what time points or life events should physicians make sure to check in with patients with AD? Options could include any or all of the following stages post AD, including before hospital discharge after an acute event, within the first few months after an event, or around surgical decision making.

4.3.2. What members of the health team are best suited to address mental health topics, and provide assessment and support?

There are many potential challenges, including time, space, referral, and insurance barriers to adding a mental health assessment and intervention component to in- or outpatient care of patients with AD. Often, patients ask for referrals for someone with experience in chronic illness or cardiac disease that, unless clinics have developed these relationships, may be challenging to provide. Can we work with our hospitals to create mental health assessment models similar to oncology models that are accessible? Do our colleagues in psychology and psychiatry need additional tools to work with our patients? What skills or knowledge have patients thought was most beneficial for their therapeutic partners to have in order to meet their needs? If isolation is a key issue in AD, can some psychological support be met by being matched with a peer mentor, a local cardiac rehabilitation support group, or a virtual community? What training do these individuals need to feel equipped to be mentors or peer network leaders? What impact does delivery mechanism have on mental health outcomes? Does a patient’s relationship (or perceived relationship) with their surgeon/care team impact mental health care provision or outcomes?

4.3.3. Involvement and/or impact on other care partners?

Another interesting topic of investigation is whether education about the physical and emotional aspects of AD provided to family, friends or caregivers can be helpful for the patient. In addition, the psychological responses and needs of caregivers in response to a patient’s AD could also be explored, as these traumatic events and sequelae often impact the family unit. Does having members of the family and friend circles who are knowledgeable about the condition make a difference in mental health outcomes?

4.3.4. How can we partner with advocacy groups?

Individuals diagnosed with a genetic etiology for their AD may have many of their needs met through a specific genetic advocacy group that is typically well equipped in providing education and support; however, for those without genetic diagnoses, there is uncertainty about how and whether they are accessing resources. There are likely ways to partner with known genetic aortopathy advocacy groups (eg, Marfan Foundation and John Ritter Foundation) to learn from and expand support education and training within mental health domains.

4.3.5. Use of technology

There are many examples of creative interventions to check in with patients or provide mental-health reflective prompts, including intensive care unit diaries, text messaging prompts, workbook development, and/or computer applications. Technology could also include use of electronic health records for screening or clinical care tools or referral popups. Ways to address gaps in access to mental health care for chronically marginalized populations needs to be included in further research.

4.3.6. Exercise

The medical and mental health benefits of exercise are well known, yet patients with AD often have questions and/or hesitancy about the safety of exercise after AD. They may also be given conflicting advice from their care providers. Many individuals may have been athletes before their dissection, thus the potential loss of identity can be quite difficult for some and is a common area of exploration in therapeutic intervention. Cardiac rehabilitation can be a productive experience to help patients gain confidence in exercise under a structured program. Referral patterns, barriers, and concerns surrounding structured exercise therapy for patients living with AD need to be explored to ensure equitable access to services. Further research needs to be performed on structured exercise and its impact on cardiovascular morbidity and mortality, but also regarding its impact on QoL and emotional coping. Additional work with regard to educational efforts is also recommended as this topic was also identified to be of importance by the AD Collaborative Education Working Group [53].

5. What clinics can do now

As the AD community continues to make progress in supporting mental health initiatives, a current call to action for clinics would be to simply start a dialogue with patients. This can be through conversation, screening tools, or even an electronic health record “smart phrase” that every patient receives as part of discharge and follow-up visit. There is tremendous room for creativity as well as partnerships with AD stakeholders. We envision any patient education would likely include:

- acknowledgment that anxiety, depression, PTSD, and isolation are real parts of living with AD with descriptions of symptoms (eg, <https://livingwithdissection.iradonline.org/emotional-information/>);
- overview of available local/national AD support resources and how to access;
- overview of local or online therapeutic resources and how to access; and
- emergency instructions if any feelings of self-harm exist.

If no local aortic dissection support groups exist, clinics may consider starting a local group in conjunction with a mental health provider, or developing a “mentor” list of patients who could serve as contacts for new patients. Advocacy groups can also help facilitate local contacts. Hosting a lecture on this topic and/or bringing up mental health topics at

case reviews may help remind staff to be proactive in conversations about mental health in their routine interactions with patients. Both local initiatives as well as society guidelines will help mental health services in the AD community evolve.

6. Study limitations

Although we attempted to be comprehensive in our review of mental health topics in AD, examining “lessons learned” from the larger cardiac literature was beyond our scope. Thus, any larger cardiac studies examining mental health issues in large cohorts where patients with AD were included likely were not examined. Similarly, if there was mention of QoL results in large studies reporting surgical outcomes, when QoL was not a major theme of the article, these likely may have been missed. Clearly, the topic of mental health outcomes in the medical literature is quite vast as a whole; thus, although we have attempted to engage with gaps and opportunities directly related to patients in AD, we acknowledge that there may be important care topics we have not touched on. Finally, studies reviewed were largely ethnically and racially homogenous populations (ie, White). Although a few studies noted gender or age differences (including two noting female patients with lower physical functioning domains), overall mental health differences related to gender, age, race, or ethnicity was not explored due to lack of data [54–56].

7. Conclusion and future directions

Coping with the trauma of AD is incredibly complex and may ultimately require that a cohort of patients be followed longitudinally with qualitative and quantitative measures to better understand the phasic nature of the impact of AD on mental health. In order to truly provide holistic care for our patients, we, as a team of health service providers and researchers, need to more fully partner with our patients to come up with best mental health practices. With any grant funding studying the medical and physical aspects of AD, it should be a priority to require a robust mental health component in study design. Larger data sets will also help to reveal any differences in mental health outcomes based on AD scenario. Examples include: Type A versus B versus prophylactic aortic surgery; thoracic endovascular aortic repair versus open repair versus medically managed; and prior aortic surgery versus first event.

Most literature addressing mental health issues in patients with AD agree that this topic needs more study, psychological assessment should be included in post-event care, and interventional studies are needed. We entirely agree and thus have attempted to outline identified gaps in current knowledge about mental health issues in individuals with AD and address some potential future research opportunities. As surgical techniques and medical therapies evolve, we must make sure that the patients experiencing these events are provided with mental health tools and resources to feel fully and holistically supported.

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