

BMJ Open Treatment and referral experiences of patients with type A aortic dissection and their families: a qualitative study

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ABSTRACT

Objectives This study aimed to analyse the experiences and feelings of patients with type A aortic dissection (TAAD) and their families during the medical treatment and referral process, investigate the entire process's needs and problems and provide evidence for improving the aortic dissection treatment system.

Design A qualitative descriptive design using a phenomenological study. Face-to-face semistructured interviews were conducted. Thematic analysis was used to analyse the interview data, which was transcribed verbatim.

Setting Department of Cardiovascular Surgery of Shanxi Bethune Hospital in China.

Participants Fifteen family groups, consisting of patients with TAAD who underwent surgical treatment and their families, were selected.

Results Three primary themes were discussed and developed. Theme 1: the experiences of medical treatment and referral (confusion at the onset; complex inner feelings and emotional expressions of the medical treatment and referral; preoperative inner conflict); theme 2: problems with the TAAD medical treatment system (the quality of diagnosis and medical treatment needs to be improved; deficiency of medical system policies and procedures); and theme 3: real demands (demands for TAAD-related knowledge and access to the disease; economic-related demands).

Conclusion Patients with TAAD and their families encounter complex inner experiences, multiple requirements and numerous challenges during the medical treatment and referral process. It is advised that the treatment and referral system of TAAD in China needs to be improved. Future research and clinical practice should standardise diagnosis and treatment training, establish a fast channel for TAAD to prioritise treatment, popularise aortic dissection-related knowledge and improve the funding system.

INTRODUCTION

Aortic dissection (AD) is a haematoma caused by blood flowing into the aortic vessels due to aortic intima injury or weakening.^{1,2} Acute onset of sharp, tearing or stabbing chest or back pain, sometimes accompanied by radiating and migratory pain, is a characteristic clinical symptom of this disease.³ The most prominent risk factor for AD is hypertension,⁴

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Few studies have investigated the experiences of patients with aortic dissection and their families during treatment, and referral process is limited.
- ⇒ This study used the interview model with family groups composed of patients and families.
- ⇒ Patients who died without surgery were excluded.
- ⇒ Because this study was conducted in a single centre and was completed in China, the findings may not apply to other areas.

and genetic diseases such as Marfan's syndrome are risk factors.⁵ It is considered immediately life threatening because it can cause aortic rupture, causing irreparable damage to vital organs and rapid death due to acute inadequate perfusion.

AD has a low morbidity and a high mortality rate, and several studies have reported that the incidence of acute aortic dissection is approximately three cases per 100 000 patients per year.⁶ However, the true morbidity and mortality of aortic dissection may have been underestimated because the epidemiological data are taken from retrospective registries, which might exclude the patients who have died before admission.⁷ Statistically, the prehospital mortality rate of AD was as high as 21%.^{5,8}

Anatomically, AD can be divided into two major types depending on the origin of the intimal tear and the extent of the dissection: Stanford type A (involving the ascending aorta, proportion 67%) and type B (not involving the ascending aorta, proportion 33%).^{7,9} Type A AD (TAAD) has a large range of aortic tears and extensive lesions, often causing dysfunction in organs, such as the heart valve, pericardium, lungs and abdominal organs. It needs a faster emergency open surgical repair time.¹⁰ Without surgery, the mortality rate of patients with TAAD increases by 1%–2% per hour on the first day of onset, reaching 50%–70% within a week.^{5,11}

Therefore, effective, rapid treatment and referral are the basis of AD patients' safety.

The anatomical classification of AD determines clinical treatment methods, including medical management, open surgical repair or endovascular interventions.¹² Therefore, emergency surgery is recommended for TAAD patients, and 90% of them have undergone surgery,¹³ which is a routine treatment. In addition, patients with AD require urgent treatment and referral to minimise tear progression by controlling blood pressure and lowering blood pressure changes.⁵

Nevertheless, clinical delays in TAAD diagnosis, treatment and referral are common. Many Chinese medical institutes are unqualified to treat patients with TAAD due to the surgery's intricacy and high risk.¹³ Therefore, the TAAD referral rate ranged from as high as 69.7%–79.0%.^{7,9} Furthermore, insufficient hospital coordination is a major issue, increasing the risk of aortic rupture and complications. One study reported that the diagnosis rate of AD is 15%–43%, and 28% of patients were diagnosed after autopsy.¹⁴ The important reasons for this may be related to the insidious onset and diverse first-stage symptoms of AD, which are easily confused with the symptoms of angina pectoris and myocardial infarction.¹⁵ Another study reported that patients who presented mainly with acute abdominal pain (4.6%) were more likely to have delayed treatment and die than those with typical symptoms.¹⁶ Some experts believe this is attributed to the clinicians' inexperience with the atypical symptoms of AD.⁷ Another study reported that insufficient diagnosis, treatment and referral systems are the important reasons.¹⁷ Overall, all of these issues place patients with TAAD in more dangerous situations, which is an important issue to be addressed.

One study from the International Registry of Acute Aortic Dissection reported that hospital environment pathways, healthcare logistics and surgical team specialisation could improve the diagnostic and therapeutic management of TAAD.⁷ Although China has made many remarkable achievements in the diagnosis and treatment of TAAD, there are still many urgent problems to be addressed, such as insufficient primary care support and underdeveloped emergency medicine systems, which can be summed up as 'irregular, immature and untimely'.¹⁷ Therefore, patients and their families may encounter multiple challenges during TAAD treatment and referral. Currently, most studies on the treatment and referral of patients with TAAD are quantitative, and qualitative research focuses on the early diagnosis and rehabilitation stage, with less attention paid to the real experiences and treatment needs of patients with TAAD in the treatment and referral process.^{18,19}

This study aimed to investigate the experiences and feelings of patients with TAAD and their families during the treatment and referral process, to discover the issues in the clinical TAAD treatment path and to provide recommendations for improving the TAAD treatment system in China.

METHODS

Study design

We conducted a qualitative, descriptive study with face-to-face, in-depth semistructured interviews, which allowed us to present participants' real feelings, experiences or perspectives.²⁰ This report adheres to the Consolidated Criteria for Reporting Qualitative research.²¹

Study participants, recruitment and setting

A family group consisting of one patient with TAAD treated in the Department of Cardiovascular Surgery of Shanxi Bethune Hospital and one family member were enrolled as the study participants using the method of convenience sampling. The inclusion criteria are as follows: (1) patients: diagnosis of TAAD in accordance with the diagnostic criteria for AD established by the European Society of Cardiology in 2014²; AD surgery was completed; and age ≥ 18 years old; (2) family members: witness to the entire process of onset of symptoms, referral and treatment and willing to participate in the interview. Exclusion criteria are: patients with an unstable disease condition and their families.

Because patients with TAAD are mostly sedated during the perioperative period, they have no complete memory. The family members' participation can fully restore the event situation and sentiments. After exhausting the interview information, another two family members were interviewed.²² Sixteen family groups expressed interest, with 15 family groups completing the interview, and one withdrew due to changes in the patient's condition.

Patient and public involvement

Of 15 family groups, we selected two representatives that met the inclusion and exclusion criteria, had some knowledge of AD and could fully express their views for the other AD patients and their families. We sent an initial draft containing participant information sheets, informed consent form interview guide and topic extraction findings to the representatives. All of their recommendations were implemented, making our study content and results closer to the true feelings of patients with TAAD and their families. Finally, we sent a summary of the results to all participants who requested it.

Data collection

We collected data between September 2021 and February 2022. QZ and WG conducted the interview, both of whom had prior interviewing experience and training. When the patients could state the onset and referral condition on their own, the investigator interviewed them at the bedside before interviewing a family member in a private conversation room. If only one family member was present, the interview was conducted at the bedside to meet the care needs of the patients.

Table 1 shows the interview guide, which was revised by four clinical experts in cardiac macrovascular surgery after a preinterview with two AD family groups. Interviewees were encouraged to share their experiences and

Table 1 Interview guide

1	Please describe the patient's presentation at the disease onset.
2	Please describe the whole process of patient treatment and referral after disease onset.
3	Please describe your inner feelings from the disease onset to diagnosis. What impressed you with the process?
4	Please share your concerns and considerations when deciding on the surgical procedure.
5	What aspects do you think are unreasonable and will affect the patient's medical treatment, referral and operation progress?

their real opinions about the treatment and referral procedure by using semistructured guided questions. Some minor changes were made as investigators continuously discussed the interview guide during data collection.

All interviews were conducted by two interviewers (QZ and WG) to ensure consistency, and the interview time was about 30 min. Digital recorders and field records were applied to record observations about participants' feelings, emotions and behaviour during the interview. All interview records were transcribed verbatim on the day of the interview. After no new themes were shown, two additional interviews were conducted to determine the data saturation.

Ethical considerations

The interviewer explained the study purpose, topic and interview procedures to all participants who met the inclusion criteria. Participants were assured that every possible strategy, such as replacing the patient's name with coding, would be used to protect their privacy. The participants' information was kept anonymous, and they could withdraw from the study at any time. We strictly adhered to the norms for excellent clinical practice. All respondents provided informed consent for participation in the study and publication of the results.

Data analysis

The interviews were transcribed verbatim and analysed using a systematic inductive interpretative technique. NVivo 11 software was used to manage all post-transcriptional interview data.²³ Using the union method, two researchers reviewed the interview content separately, considered and analysed all the data repeatedly and revealed the topics through the content analysis.^{24 25} Repeated concepts or meaningful statements were extracted and coded, and the results were grouped into subthemes based on descriptive content and reviewed collaboratively with another author. After these subthemes were further integrated, the themes were sublimated. Following the completion of subject extraction, the members of the research group read and gave their opinions. If the opinions are not unified, the groups will hold discussions until the opinions are unified to ensure the accuracy of the analysis.

RESULTS

Fifteen family groups with the matching codes N1~N15 completed the interview. There were nine male and six female patients, aged 19–71 (47.33±13.95) years. The interview took place 4–49 days after surgery, with a median of 12 days. Nine patients had developed hypertension, while three had coronary heart disease, renal failure and Marfan's syndrome, respectively. Only three cases had a history of coronary stent implantation, kidney transplantation and caesarean delivery in the last 3 years. **Table 2** shows the general information and disease characteristics of the participants.

The research finally extracted three first-level themes and seven second-level themes. The theme relationship is shown in **figure 1**.

Theme 1: the experiences of medical treatment and referral

AD is one of the most critical cardiovascular diseases, and patients and their families go through a lot of inner experiences during the medical treatment and referral process. Their emotions will change dramatically as disease treatment progresses. The treatment timeline is divided into three stages: onset, medical treatment and referral, and before operation.

Subtheme 1A: confusion at the onset

The onset of AD is acute, and the patients and their families are frequently confused about the sudden onset of symptoms, which is due to lack of sufficient warning of the onset.

N5: 'I have not been sick before. I sat for a while, but this did not help. I thought I got a stitch. I did not anticipate such severe disease'.

Another reason is that the symptoms are atypical, which is similar to gastrointestinal disease, spinal disease, epilepsy, etc.

N3: 'She mentioned having back pain a week ago. We all thought it was due to spine pain and then gave her a massage. We did not expect this severe disease, we suspected it was acute enteritis or diarrhoea'.

N5: 'My back pain was unbearable at that time, and I even experienced bone pain. I remember that as I was giving birth, the doctor was unable to administer the anaesthetic and my back was hurting. I assumed it was due to delivery'.

N3: 'She suddenly convulsed for no reason; we all thought it was a seizure'.

Subtheme 1B: complex inner feelings and emotional expressions of the medical treatment and referral

The symptoms of AD are urgent, and treatment needs to be done immediately. Thus, the family members always have a sense of crisis.

N2: 'I felt that the disease was so critical that if I came to the hospital half an hour later that day, the result would not be imagined'.

Table 2 Participants' general information and disease characteristics

Number	a	b	c	d	e	f	g	h	i	k	l	m	n	o
1	Young male	iii	Worker	Wife	37	0.5	1	Hypertension	NA	3	1	Before dawn, sleeping	Chest and back pain, unable to walk	NA
2	Middle-aged male	ii	Sportsman	Son	12	0.2	1	Coronary disease	Coronary stent implantation	3	1	Toward evening, play mah-jong	Dizziness and slow reaction	NA
3	Middle-aged female	iii	Unemployed	Daughter	49	0.3	1	Renal failure	Kidney transplant	3	4	In the evening, before falling asleep	Sudden convulsions	Minor back pain a week ago
4	Young male	ii	Worker	Mother	27	0.7	1	Hypertension	NA	3	2	In the morning, wake up	All over pains	NA
5	Young female	ii	Teacher	Husband	23	0.5	1	NA	Uterine-incision delivery	11	6	In the evening, at rest	Intolerable back, spine pain	NA
6	Middle-aged female	iv	Unemployed	Son	28	0.25	1	Hypertension, diabetes mellitus	NA	1	1	Post pentaculum	Shoulder acid sleepy, left upper limb numbness, tight breath, shortness of breath, abdominal discomfort	NA
7	Elderly female	iv	Unemployed	Daughter	11	0.5	1	Hypertension	NA	3	0.5	In the afternoon, Before the nap	After vomiting, breathe hard, cannot lie flat	Frequent nausea and vomiting for half a year
8	Middle-aged female	iv	Farmer	Husband	11	0.3	1	Hypertension	NA	1.5	0.9	Before dawn, sleeping	The unbearable front chest pain, gradually extends to the lower limbs and the whole body	NA
9	Middle-aged female	iv	Farmer	Son	8	1.2	2	NA	NA	5	1.6	In the evening, after dinner	Chest stuffy, pain from throat to sword	NA
10	Young male	iii	Worker	Wife	18	0.6	2	NA	NA	48	2	In the morning, post pentaculum	Sweat, weak, stuffy chest, toothache, abdominal pain	NA
11	Young male	v	Unemployed	Father	4	0.6	1	Marfan's syndrome	NA	3	3	In the afternoon, post prandium	Severe vomiting, chest pain	NA
12	Middle-aged male	iii	Policeman	Wife	6	0.6	1	Hypertension	NA	240	2	Before dawn, before going to bed after drinking	Intolerable back pain	NA
13	Middle-aged male	iii	Farmer	Wife	7	0.1	1	Hypertension	NA	1	0.6	At noon, ante prandium	Stuffy chest and back	NA
14	Middle-aged female	iv	Worker	Husband	4	1	2	Hypertension	NA	5	0.3	Before dawn, working	Thoracic back pain, vomiting	NA
15	Young male	iii	Worker	Father	17	0.5	1	Hypertension	NA	2	0.9	In the evening, resting	Chest and back pain, weak	NA

Notes: a: age and gender; b: highest level of education (i: postgraduate, ii: college/university, iii: high school, iv: primary school, v: missing); c: occupation; d: relationship to the interviewee; e: interview moment (days after surgery); f: time of arrival at the first medical institution (hours); g: number of referrals; h: medical history; i: history of surgery; k: time of onset to diagnosis (hours); l: time of disease diagnosis to operation (days); m: time and state of disease onset; n: first symptoms; o: early-stage atypical symptoms.

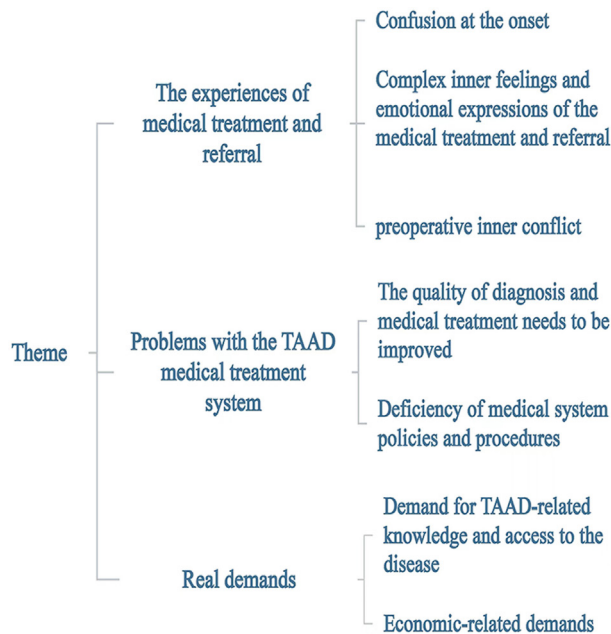


Figure 1 Themes diagram. TAAD, type A aortic dissection.

N14: ‘After being diagnosed, we want to have surgery as soon as possible because time is life’.

The arrival of the ambulance personnel will give the patients a sense of security.

N2: ‘I was not so scared in the ambulance because there were paramedics to save me’.

During the medical treatment and referral, they felt horrified, fearful, sorrowful and sympathetic. However, for the patients who have had a long course of AD and repeated referrals, their emotions will gradually change from fear and sadness to numbness.

N3: ‘We had heard that it was a terrible disease. We were shocked and in a bad mood. Everyone cried’.

N11: ‘I felt very afraid, because only the serious patients were transported by ambulance. Those with mild conditions can be treated in the local hospital’.

N11: ‘He was so pathetic, suffering from a disability (Marfan’s syndrome), and now he has been diagnosed with a severe disease; poor people have such a hard life’.

N12: ‘I could not cry at that point. I felt numb, with no emotions in the face of repeated serious illness notifications’.

Subtheme 1C: preoperative inner conflict

Because AD is so dangerous, family members are frequently subjected to psychological pressure, and they must make urgent surgical decisions. All patients and their families were eager for surgery, but due to poor physical indicators, insufficient surgical resources and other factors, they were compelled to wait, resulting in ambivalence.

N3: ‘Definitely, the more stable the vital signs, the safer the operation. If the delay is too long, there is a risk of blood vessel rupture. But her blood oxygen saturation level has just reached the standard, and we struggled and wanted to wait’.

N7: ‘Many doctors advised me at that time that the situation was critical and that I needed to have an emergency operation. However, the operation could only be done the next day, which meant I would have to wait all night, and I was afraid that my mother would deteriorate during this period’. (burst into tears)

When making surgical decisions, family members must consider financial implications, surgical risks and the patients’ general condition.

N9: ‘The operation is expensive, and it may be futile, but if I give up, I may lose my mother’.

Theme 2: problems with the TAAD medical treatment system

We found that the inner feelings and emotional expression of patients and their families are complex, through the improvement of the interview content. However, we found that there are problems in the treatment and referral process system of AD. These issues are divided into two categories: ‘the quality of diagnosis and medical treatment needs to be improved’ and ‘deficiency of medical system policies and procedures’.

Subtheme 2A: the quality of diagnosis and medical treatment needs to be improved

The discrimination ability and sensitivity of AD symptoms by doctors, triage nurses and image technicians are insufficient, impacting the quality of diagnosis and treatment and influencing the judgement of the subsequently referred hospital.

N5: ‘The doctor stated he had no idea what the disease was and had to examine each patient individually. We all breathed a sigh of relief when he told us the results were fine, but after checking CTA (Computed Tomographic Angiography), it was diagnosed as aortic dissection’.

N5: ‘The triage nurse asked us to visit the gynaecology and obstetrics department. We arrived upstairs, and the doctor said that it was not a gynaecological disease, so we came down’.

N8: ‘The imaging technician said, “What disease is it? Why is it necessary to perform a colour Doppler ultrasound?” He refused to render services’.

N8: ‘The endocrinology department treated in accordance with the previous diagnosis (acute pancreatitis), which exacerbated the situation’.

According to the patients and their families, they were not actively treated after being diagnosed.

N3: ‘From the diagnosis through the next morning, the doctor only appeared once, and stated that

additional examination was needed. There were no further treatment measures after the examination results came out, and the doctor did not consult other departments’.

The doctor–patient relationship is not harmonious. The medical staff’s authoritative tone hinders patient and their family compliance and expression of needs during the diagnosis and medical treatment process.

N3: ‘The doctor passed by occasionally and would urgently exclaim, “Cannot sit up!” He did not say why she could not sit up, but my mother said sitting up feels better. Then I helped her sit up and rubbed her back’.

Subtheme 2B: deficiency of medical system policies and procedures

Emergency and large payment procedures are mechanised. WeChat, bank cards and other payment methods adopted by the hospital have affected the convenience of emergency and large payments due to the problem of transfer limits and account delays.

N7: ‘We were too anxious to bring bank cards. We assumed we could use WeChat to pay. But WeChat could not pay so much, and finally, the money was pooled by many people’.

N14: ‘There is a limit on the bank transfer amount, and the cross-bank transfer time is slow’.

The mutual recognition of the medical examination results between hospitals is low, leading to repeated examinations after referral.

N1: ‘I had another examination when I arrived at the emergency department, because the previous examination results were not accepted’.

The acute AD treatment process under COVID-19 prevention and control is not optimised. The characteristics of the emergency treatment and the characteristics of the principle of COVID-19 prevention and control need to be further weighed.

N7: ‘I do not understand. Treatment of the disease was very urgent, but it took so long for the surgery because of waiting for COVID-19 nucleic acid results’.

There is a problem of mutual prevarication between doctors and ambulance staff in the process of ensuring the safety of patients’ referrals.

N15: ‘At that time, ambulance personnel requested the doctor to go, but the doctor said he was not responsible’.

After the diagnosis, the patient needs to be referred to a superior hospital with surgical qualifications for treatment. However, lower hospitals did not know the list of qualified hospitals, and patients were even transferred to the hospital without surgery qualifications.

N8: ‘At the beginning, I prepared to go to the nearest provincial hospital, and then the doctor helped to call; we finally know that your hospital has the ability to operate’.

N14: ‘His back was in pain, and the doctor thought it might be AD and suggested transferring to the local hospital. We went there and he was diagnosed, but the hospital did not have the ability to operate, so we came to your hospital again’.

The number of ambulances is insufficient.

N4: ‘After getting through the emergency call, I was told that there was no emergency car now’.

N15: ‘I could not get an emergency car, and I had to ask my son to drive over’.

Theme 3: real demands

Although the hospital has adopted a series of humanised services for acute and critical patients, we have found that the current service level cannot meet the actual needs of patients with AD and their families in the process of medical treatment and referral. We divided these unmet needs into two aspects: ‘demand for disease knowledge and knowledge access methods’ and ‘economic-related demand’.

Subtheme 3A: demands for TAAD-related knowledge and access to the disease

They want to have the ability to recognise the symptoms in the early stages of the disease, and understand the main causes of AD, hoping to avoid and slow down the occurrence and recurrence of AD.

N2: ‘We want to know what the first-onset symptoms of this disease are?’

N14: ‘I want to know what the symptoms of AD are, so that when similar symptoms occur, we will know whether the disease is very serious, and we need to go to the hospital immediately’.

N13: ‘He has been taking medicine regularly since he was diagnosed with hypertension, and I do not know exactly what caused the disease’.

N11: ‘Why does this disease occur? Is the tear caused by vomiting? If it is not serious vomiting, how is it?’

AD is not common compared with coronary heart disease and hypertension, but the mortality rate is extremely high. Patients and their families want to have access to scientific and professional knowledge.

N9: ‘When I told the village doctor that my mother had an aortic dissection, and he asked what the disease was, many people did not know’.

N13: ‘Chronic diseases will be taught by doctors from community health service stations, but no one else knows about the disease (AD), so we need your professionals to preach’.

In addition, the family members hope that the explanation of the patient's disease knowledge should be as simple as possible to reduce the psychological burden of patients.

N6: 'Just tell him what disease it is, and do not talk too much. It makes sense that the ignorant are fearless; too much information will add to her troubles and pressure. More education should be given to family members'.

Subtheme 3B: economic-related demands

Raising huge surgical costs in a short time puts great financial pressure on the families of AD patients. They hope that the hospital can reasonably set up procedures of large payment according to the patient's conditions, economics and other special circumstances.

N9: 'We were scared when we heard the cost because we did not have much cash. We hope that the hospital will allow us to pay in a few days'.

N10: 'Only the deposit was up to 160 000 yuan, and we did not have enough time to raise so much money. For this reason, we stayed in the emergency department for an additional 2 days'.

Due to the AD stress events, it is difficult to complete the medical reimbursement in time, and they hope that the reimbursement procedure for referral and medical insurance could be optimised.

N10: 'At that time, the child's condition was too dangerous; I did not consider reimbursement. When we went to the medical insurance department, we were told that only 45% could be reimbursed instead of 60%'.

DISCUSSION

Importance of AD family members' experiences

Acute AD is a huge stress event for the patients and their families. Patients are mostly in a state of analgesia and sedation due to the needs of the early stage of diagnosis and treatment, and their consciousness is impaired. Hence, their medical treatment, referral and surgical decisions are often made by their family members. Therefore, this study reflects the complex inner experiences of the patient's families, including confusion at the time of onset; sense of crisis, panic, fear, sadness and numbness during the medical treatment and referral; and preoperative contradictions, suffering, trade-offs and choices.

This complexity is generated for two reasons. On the one hand, the onset of AD must be treated as an emergency, and accelerating the efficiency of medical treatment and referral puts forward higher requirements for family members (or escorts), including high execution, and high ability to timely cooperate with doctors for referrals and make rational surgical decisions.^{26 27} However, the medical personnel are currently more prone to adopt

the traditional medical decision-making style in the AD diagnosis and treatment process, while ignoring the inner feelings and emotional expression of the family members. In addition, due to the lack of knowledge and social support related to the diseases, the actual participation of family members is minimal, and it is easy to have various negative emotional experiences.²⁶

According to the family system theory, the health crisis of family members affects the family's general function and limits the family's comprehensive response ability to diseases.²⁸ Therefore, considering the unpredictability and uncontrollability of AD progress, medical professionals should also pay attention to the inner experiences of family members while stabilising patients' emotions. Providing patients with disease knowledge and rehabilitation guidance in a timely manner is of great significance to improve patients' inner experience and family flexibility and accelerate the rehabilitation process of patients with AD.

Standardised diagnosis and treatment training

Timely and correct diagnosis of the disease is the basis of saving the life of patients with AD. Once a misdiagnosis or missed diagnosis is made, the best treatment time may be missed, increasing the risk of death.²⁹ We found that emergency physicians, triage nurses and image technicians had insufficient ability to differentiate AD symptoms, and there are the issues of misdiagnosis and delay in diagnosis and treatment, which are similar to Yaru Xiao's findings.³⁰ The objective reason may be that AD is characterised by sudden chest and back pain. Hence, it is easily confused with acute coronary artery syndrome and acute pulmonary embolism. In addition, the incidence of AD is low, and according to the scope and degree of dissection tears, the symptoms are diverse and atypical, such as abdominal pain and lower limb pain, making it difficult to identify and triage early.¹⁵ The American College of Cardiology and American Heart Association proposed using the AD risk score for the initial diagnosis of AD in 2010,³¹ to make the early diagnosis of AD more accurate and rapid. In recent years, China has steadily implemented the risk score, which has proven to have high specificity and sensitivity.³²⁻³⁴

However, this study found that the subjective reason for misdiagnosis or delay in diagnosis and treatment was that emergency medical staff did not understand or pay attention to AD symptoms, affecting their treatment behaviours and communication effects, thus further extending the referral time, influencing referral safety and survival rate, which is one of the important factors hindering the progression of AD diagnosis and treatment in China.¹⁷ Therefore, it is urgent to conduct AD standardised diagnosis and treatment training and to strengthen the knowledge and skills of AD differential diagnosis and treatment. It is most important to improve emergency medical staff and medical technicians' alertness to AD. In addition, it is vital to cultivate a standardised talent team suitable for the disease symptoms

of patients with AD in China to continuously improve the quality of diagnosis and treatment and safeguard patients' life.

Fast channel for AD diagnosis and treatment

Creating a fast channel of AD diagnosis and treatment and ensuring its smooth operation is an effective strategy to accelerate AD treatment.¹⁷ However, we found many issues with the AD referral process. For example, transferring to a hospital without surgical qualification and being unaware of the referral location demonstrates that the regional medical association model is immature, and the low trust of medical examination results between the 'upper' and 'lower' hospitals is one of the flaws of this model. This might have resulted from the inadequate AD examination and referral network and insufficient integration of medical resources.

In addition, one study reported that transferring AD patients to experienced hospitals can reduce fatality rates by 7.2%.³⁵ However, there are potential risks during the process, such as increased blood pressure and dissection aneurysm rupture. The referral system is equipped with emergency personnel and equipment, which can ensure the safety of patients with AD during referrals and effectively reduce the risk of referral, and is a crucial link in the AD diagnostic and treatment channel. However, we found that there are issues between the referral doctors and 'private' emergency personnel, such as negative referrals and shirking of the referral duties, which hampered the continuity of diagnosis and treatment. The main reason could be a lack of ambulance cars, and the ambulance system does not meet the needs of patients for cross-regional referral, resulting in non-professional referral of ambulances without operating licenses, which undermines patients and their families trust in the emergency system disrupts the order of emergency referral. The most important thing to remember is that the non-professional referral cannot ensure the blood pressure, pain, and thoracic and abdominal pressure management of patients with AD, which could cause the sudden rupture of the dissection.

Currently, only a few studies have reported the development of AD diagnosis and treatment fast channels in China,^{36–39} while most areas have not yet formed mature channels. Therefore, it is necessary to take advantage of the Regional Medical Association in the future, clarify the list of hospitals with AD surgery qualification and its radiation scope, strengthen the management of the emergency system, standardise the AD referral process and realise the seamless connection of patient's conditions, examination and referral between hospitals, which can further form and popularise the fast channel of AD diagnosis and treatment, and improve the quality of care. However, in the framework of COVID-19, it is essential to examine how to balance the features of AD emergency treatment with the common principles of epidemic prevention and control.

Improvement of disease-related knowledge and funding system

The treatment of AD is highly time dependent. Studies have reported that the mortality rate of untreated Stanford A AD patients increased by 1%–2% per hour, with 18%–21% dying before arriving at the hospital.^{5 7 40} As witnesses to the disease, the family members play an important role in the process of identification and treatment. This study found that family members hoped that medical professionals would disseminate and publicise AD knowledge, and they requested to understand the aetiology of AD and learn the ability to identify the initial symptoms to identify the occurrence of AD as soon as possible. This could be because the families experienced major critical events that stimulated their desire for knowledge.⁴¹

From another point of view, it shows that the existing knowledge promotion of advertising diseases is not enough, which may be related to the low incidence of AD that is easy to be ignored,⁴² the late start of domestic AD research, the lack of practical experiences and the flawed system.¹⁷ Consequently, it is recommended that the authoritative medical institutions should take the initiative in establishing a publicity framework and visualising the publicity content. Furthermore, it should be disseminated through community, rural doctors and network channels to strengthen public awareness of the disease, shorten the prehospital delay time and improve the long-term survival rate of patients with AD.

In addition, this study found that increasingly high costs in a short period has brought great economic pressure on families of patients with AD. However, family members are committed to AD stress events, and it is difficult to complete the medical reimbursement in time, which reduces the reimbursement ratio and increases the financial burden of the family. Therefore, it is recommended to optimise the reimbursement procedures. Currently, medical security for rare diseases is still improving.⁴³ Whether to increase the AD reimbursement ratio, extend the reimbursement filing time and increase the amount of severe disease treatment subsidies still need further consideration by relevant departments.

Methodological rigor

Increasing the rigour of qualitative research methodologies ensures the authenticity of data collection and the reliability of data analysis. It was demonstrated to guarantee the credibility of the study findings.²⁰ Before the interview: the main researchers have mastered data collection methods and data analysis techniques for qualitative research. On the basis of reviewing the relevant literature and consulting the clinical experts, the interview guide was preliminarily determined after the preinterview. During the interview: create an appropriate interview atmosphere and reduce interruption as much as possible to avoid invalid interviews. Timely questioning and repeating of the respondents' statements minimise the researchers' bias. After the interview, we sorted out

and transcribed the recordings and wrote the reflection notes. Data analysis using the researcher union method improved the credibility of the results. The classified data was returned to the respondents to ensure authenticity of the data. Article writing: the first author translated the theme from Chinese to English. The equivalence of subject translation was validated through discussions between other authors and a medical major, native English doctor.

Limitations

There are some limitations to this study. The patients who died in the prehospital settings without surgery were excluded, which might have impacted the comprehensiveness of the study results. However, based on the humanitarian spirit and reality, we cannot currently avoid this situation. Second, although the patients and their families provided information, the patients only remembered the scene at the time of the onset and the initial stage of the treatment due to the rapid development of the disease, and the family members provided most of the experiences of medical treatment and referral. Role discrimination was not done in the results, which is one of our study's limitations. A single hospital was chosen, limiting the sample's representativeness since the research institute is the sole autonomous hospital in the province. It is recommended to conduct multicentre qualitative research to find regional variations and commonalities in the AD treatment and referral process.

CONCLUSION

Through interviewing patients with TAAD and their families, three themes were extracted: the experiences of medical treatment and referral, problems with the AD diagnosis and medical treatment system and real demand, suggesting that the AD diagnosis and treatment system in China needs to be further improved. Future studies and clinical practice should concentrate on standardising training in AD diagnosis and treatment, forming a fast channel for AD diagnosis and treatment, boosting the dissemination of AD-related knowledge and improving the funding system.

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Patient consent for publication Not applicable.

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