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Opinion Research
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Report of Findings from Opinion Research among Heart Valve Disease Patients

Conducted for The Alliance for Aging Research

June 2016

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Introduction and brief methods

More than five million Americans are estimated to have heart valve disease (HVD)[1], and disproportionately impacts older adults. The Alliance for Aging Research (AAR) asked Belden Russonello Strategists to conduct opinion research to learn about the experiences of heart valve patients as they are diagnosed and seek treatment.

The following report presents the findings of a two part research project: a survey conducted among 406 individuals with a diagnosis of heart valve disease, using the Harris Panel and additional partner panels; and two focus groups of HVD patients. The questionnaire for the survey and the moderator's guide for the focus groups were written in close consultation with AAR and advisors.

The Harris Panel provides a robust representative sample of the general population of the US and includes information about participants' health conditions. An invitation to take part in the survey was sent only to those individuals pre-identified as having HVD, and we confirmed with the respondents about their diagnosis before including them in our sample for this study. Respondents were contacted and filled out the questionnaire online March 29 to April 7, 2016.

The 406 respondents to the online survey are younger than we project the actual population of HVD patients to be (See table 1 in Appendix C: Methodology). The data have been weighted to correct as much as statistically feasible, but cannot correct entirely for underrepresentation of older respondents. In reporting the findings of this research project, we break down the respondents by demographic variables such as gender, age, income, and education. Also we have classified respondents in two disease categories: those with the following diagnoses were classified as having *serious heart valve disease*: aortic stenosis, mitral stenosis, aortic regurgitation or insufficiency, pulmonary stenosis, pulmonary regurgitation or insufficiency, tricuspid regurgitation or insufficiency, and tricuspid stenosis, or other heart valve disease. They make up half the total. Respondents who only have mitral regurgitation or insufficiency make up the other 50% of the total and are referred to in this report as having *less serious disease* or *MVR only*.

The focus groups were held in New York City and Chicago on June 6 and 7, 2016, and moderated by Nancy Belden. The men and women who participated are all heart valve patients, with issues ranging from atrial fibrillation to life threatening disease. The sessions were tape recorded and annotated transcripts prepared. Verbatim quotations are included in the report, illustrating the survey findings in the words of patients.

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[1] Nkomo et al. 2006. Burden of Valvular Heart Diseases: A Population-Based Study. *Lancet* 368(9540):1005-11.

Executive summary

Limited awareness of valve disease: More than two thirds of the Americans with a diagnosis of heart valve disease in our survey knew a limited amount or nothing about valve disease prior to their diagnosis. Lack of awareness was particularly high among people with lower incomes.

Diagnosis with and without symptoms patients recognize: The survey reveals that many sufferers of valve disease do not recognize their symptoms as indicative of a problem until they stumble on the finding in a doctor's office. Six in ten – especially older people and those with mitral valve regurgitation (MVR) only – were diagnosed with heart valve disease only because they went to see a health care provider for a regular checkup or some other issue.

The other four in ten had symptoms that prompted them to make a medical appointment or had gone to an emergency room with serious symptoms. In the focus groups we heard accounts illustrating the variety of ways patients' disease was discovered, ranging from emergency surgery to a checkup prior to dental surgery.

Reliance on cardiologists: According to the survey, HVD patients rely on cardiologists, and to a smaller degree their "regular" doctors and medical staff, for diagnosis and ongoing care – and as their main source of information and decision making about treatment.

High levels of satisfaction with treatment: In our survey, about half have had some surgery or procedure and four in ten have received medication relative to their valve disease. Among those who have been treated, a full 96% express satisfaction – including 78% who are *very* satisfied.

Barriers to care: One third of the patients in our survey says simply understanding "how to go about getting treated" for HVD is a problem. A quarter says it does not have family or friends who "can help me enough." Other barriers for smaller numbers of patients include a paucity of medical facilities and/or doctors with the expertise near to them; cost; and difficulty getting referrals and appointments with experts.

Information sources: Half have used the Internet to search for information about valve disease. Among that half, two thirds have visited medical sites such as WebMD and half have used sites or big institutions such as the Mayo or Cleveland Clinic. About three in ten mention visiting websites of non-profit or patient organizations such the Alliance for Aging Research and others for information.

Outside the Internet, the most frequent suppliers of information are health care providers. And they disseminate information to their patients the old fashion way – during in-person visits –

82% of the time. While remote contact is less common, portals such as My Chart do show up as a way HCPs communicate with their patients (17% in this study), followed by phone calls and email.

A plurality (about four in ten) says the majority of the information it has found has come from the health care providers, about a quarter has found most of information independently, and about two in ten say a mixture of the two. While physicians are clearly important providers of education for their patients, several focus group participants noted that nurses and physicians' assistants are often the more informative sources.

Little help from services: The individuals in our survey do not appear to be looking for help outside their one-on-one relationships with their health care providers. Small numbers of the patients received help from services such as rehabilitation services, medication and financial assistance programs, or support groups. And few express a desire for any particular one of these.

Living with limitations because of HVD: Slightly more than half (54%) the heart valve patients report experiencing some limitations in their lives related to their condition, such as problems with sleep, shopping or doing other things outside the home, getting enough physical exercise, or having a sexual relationship. The proportion of patients reporting limitations drops to about four in ten (42%) after they have received treatment. Patients with more serious HVD are more likely to report living with limitations before treatment (63%), and to see those limitations drop (they decline to 49% after treatment).

Detailed findings

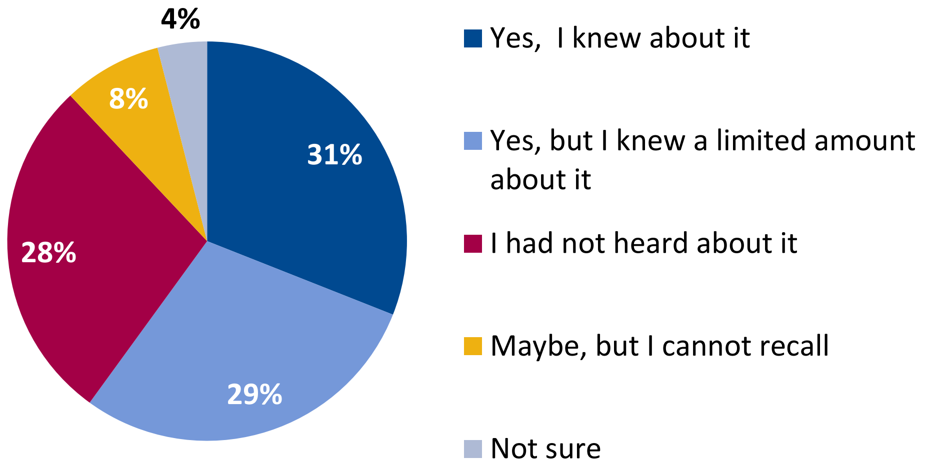
A. Awareness of heart valve disease

More than two thirds of the valve disease patients in our survey knew a limited amount or nothing about valve disease before their diagnosis.

Prior to being diagnosed, nearly seven in ten patients had little or no knowledge of the disease. Four in ten HVD patients had not heard of the ailment (28%), cannot recall if they had any knowledge of it (8%), or are unsure (4%). Another three in ten (29%) say they knew only a limited amount. One third (31%) say they did know about the disease.

Awareness of Heart Valve Disease

Among Heart Valve Disease Patients



Q4. Before your valve disease diagnosis, had you heard of valve disease?

Patients with serious valve disease were a great deal more likely to be aware of it prior to diagnosis. Fully 41% of those individuals say they knew about it, while only 17% of those with less serious conditions were aware.

A lack of pre-existing awareness was especially high among people with incomes under $50,000: 44% said they had not heard about it. This compares to 23% and 20% among patients who had not heard of HVD with incomes between $50,000 and $100,000 and those with incomes over $100,000 respectively.

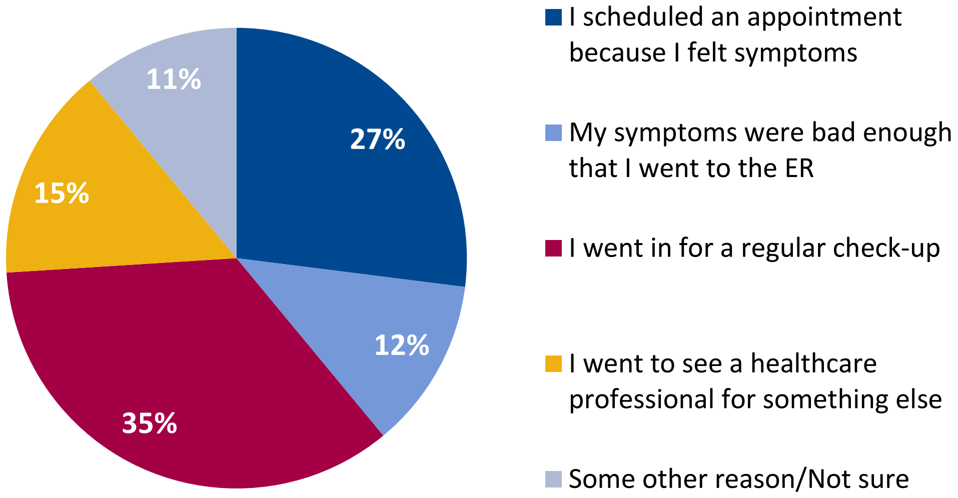
B. Getting a diagnosis

> I didn't know what it was, I knew I had symptoms, but I didn't know what those symptoms meant… -- Bill, New York

A majority of the patients in our study were diagnosed with heart valve disease only because they went to see a health care provider for a regular checkup (35%) or some other issue (15%) – or they are unclear about why they went to see a doctor (11%). The remaining four in ten recall having symptoms that prompted them to make an appointment (27%) or to go an emergency room (12%).

Reason for Seeing a Healthcare Professional

Among Heart Valve Disease Patients



Q5. Think back to the *first* time a healthcare professional told you that you might have valve disease. Which one of the following reasons best describes your reason for seeing a healthcare professional that day?

Individuals with MVR only were more likely to be diagnosed when visiting the doctor for a checkup (45%) or other reasons (28%), while those with serious HVD were more likely to be examined because they had symptoms that prompted them to go see a HCP (34%) or go to an emergency room (14%).

Women are more likely than men to say they were unsuspecting, that is they were diagnosed when in the doctor's office for something else (20% women, 11% men) or some other unrelated reason they cannot recall (11% women, 4% men).

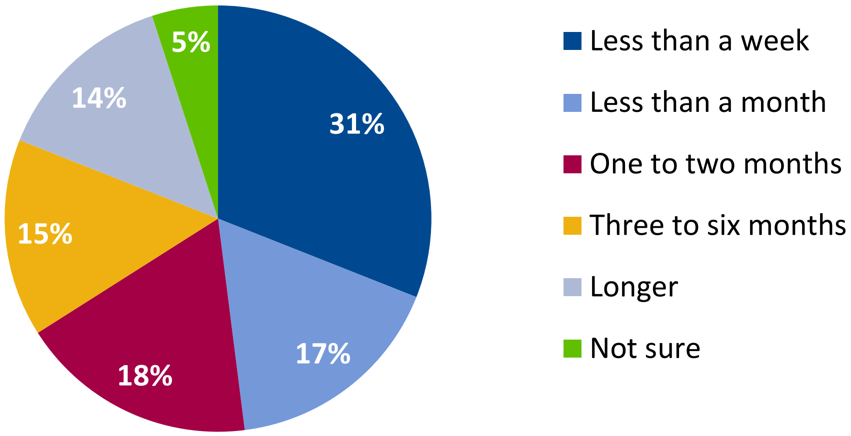
The participants in our focus groups provided good examples of the myriad ways HVD sufferers receive diagnoses, from suspecting there is a heart issue to completely unanticipated situations.

> (It became) suspicious about a year ago. Probably about three months ago I was diagnosed. They did some stress tests, the echo thing, and also the electronic one, and then the halter pack, and the 24 hour and two week one. I guess the regurgitation is caused by cardio myopathy... there's a lot of family history of cardiac disease, a lot. .. transplant list.. .my sister had aortic stenosis.. Grandpa died of a heart attack; it goes on and on and on. We don't mess around with hearts. – Jack, New York
>
> I needed major dental work done, and my dentist wanted me to be checked before we started. – Anna, New York
>
> I don't remember anything (suspicious). My parents and my brother all had high blood pressure and other problems, and my doctor said, have you ever been to a cardiologist? And I said no. So I went to a cardiologist and he told me I had a heart murmur...he said some people get it later, some people don't, and whatever.—Toby, New York
>
> I was on a treadmill, I was going four (miles an hour). I knew I was getting older though, but it was too much...all of a sudden it just got too much; I couldn't even take it to four. – Renee, New York
>
> I did all these tests, and nothing was showing. I was having palpitations more and more at night, but whatever. No shortness of breath, chest pain. All of a sudden they said, let's try something, let's try one last thing. Bam! Why didn't they do that first? I could've been dead! 'Cause they told me, you have a widow maker. – Jim, Chicago

About half the respondents in the survey who sought a diagnosis because of symptoms (48%) had experienced those symptoms for less than a month – including 31% who had symptoms for less than a week before they were diagnosed with HVD. Another 18% report having had symptoms from one to two months before their diagnosis.

Duration of Symptoms before Diagnosis

Among Patients Who Saw a Healthcare Professional Due to Their Symptoms



Q6. [IF WENT TO HCP BECAUSE OF SYMPTOMS] How long did you have symptoms before you were first diagnosed? (N=201)

In our sample, gender again makes a difference, as men were more likely than women to be diagnosed quickly. Among the respondents who sought help because of symptoms, two thirds of men were given a diagnosis within a month (38% within a week plus 22% within a month), as compared to one third of women (21% a week and 10% a month).

Another difference is in size of the community where one lives. 42% of big city residents with symptoms found out about their disease within a week, compared to 22% of suburbanites and 25% of rural residents.

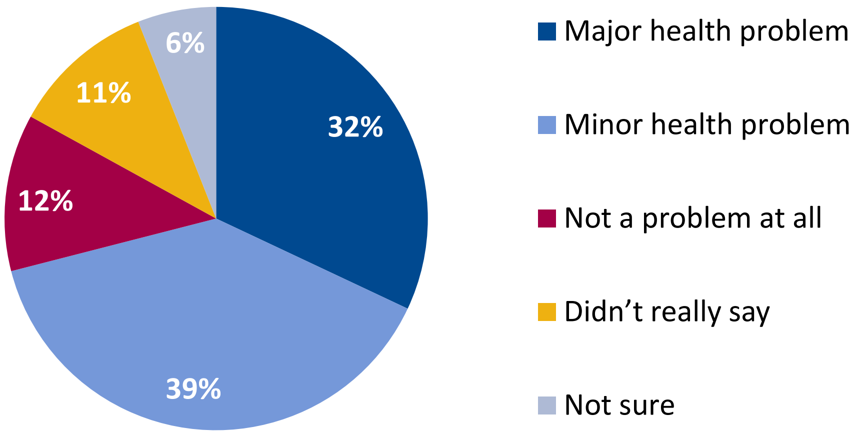
One third (32%) were advised that their condition was a major health problem and another four in ten (39%) that it was a minor problem.

Men were much more likely to be told that their disease was a major health problem (46%) compared to women (16%). Those with a high school education only were less likely to recall being told their condition was a major problem (21%) as compared to college graduates (42%) and individuals with graduate school training (37%).

Not surprisingly, patients who have MVR only have largely been told that their condition is a minor health problem (44%) or not a problem at all (21%), and 36% that it is major. This contrasts with 44% of those with serious HVD were told it was a major health problem, and 36% that it was a minor one, and 6% not a problem at all.

Severity of Valve Disease as Relayed to Patients

Among Heart Valve Disease Patients



Q9. When you were first diagnosed with valve disease, did your healthcare professional tell you it was a minor health problem, major health problem, not a problem at all, didn't really say, not sure?

About a third of the individuals in our study report that they have one or more other conditions that are risk factors for HVD. Eighteen percent have had heart attacks or heart failure; 13% have congenital heart disease; and 10% have had rheumatic fever. Fewer have experienced infective endocarditis (7%) or have had radiation to the chest (6%). And only 3% report intravenous drug use.

Other Medical Conditions

Q3. Which, if any, of these do you have now or have you experienced in the past?	
Heart attack or heart failure	18%
Congenital heart disease/birth defect	13
Rheumatic fever	10
Infective endocarditis	7
Radiation treatment to the chest	6
Intravenous drug use	3
None of these	62
Not sure	4

Respondents under age 55 are more likely to indicate they have experienced each of the risk factors we included.

C. Problems associated with HVD – pre and post treatment

We asked the patients in our survey about symptoms that might have sent them to the doctor. Among individuals who saw a HCP because they felt symptoms (first column on the following table), four symptoms we listed were common: fatigue/tiredness (47%); atrial fibrillation or palpitations (46%); shortness of breath (45%); and chest pain upon exertion (40%). Other symptoms were dizziness or fainting (30%) and swelling of their extremities, abdomen, or veins in the neck (25%).

> I was diagnosed - actually tomorrow it'll be two years - and I knew I had this because for the time I was having difficulty taking steps, and getting out of breath. So I went to a cardiologist and he told me that I needed a valve replacement. I went right to the cardiologist. – Bill, New York

Among those who were seen because of symptoms, fully 80% who have MVR only reported AFib, but only 34% of those with serious HVD reported AFib. The patients with more serious HVD are more likely to report that their symptoms included fatigue and tiredness (53%), shortness of breath (48%), and chest pain when exerting themselves (48%).

The women in our study were much more likely to report AFib or palpitations (60%) than were the men (36%).

The story is slightly different among unsuspecting patients who were diagnosed with HVD when they were seen for other reasons (second column on table). About a third identifies each of three issues – fatigue, AFib, and shortness of breath – as problems they associated with their HVD *after* they were diagnosed. But only 11% say they had experienced chest pain when exerting themselves and 15% reported swelling.

Symptoms Recognized Pre- and Upon Diagnosis

Q7. Before you were diagnosed with valve disease, what were your symptoms? / Q8. After your valve disease diagnosis, did you realize that you had experienced any of the following symptoms of valve disease that you had ignored or attributed to something else?

	Those who went to a HCP for symptoms pre-diagnosis (N=201)	Those who realized their symptoms upon diagnosis (N=163)
Fatigue/tiredness	47%	34%
Atrial fibrillation and/or palpitations (irregular heartbeat)	46	33
Shortness of breath	45	31
Chest pain when you exerted yourself	40	11
Dizziness or fainting	30	10
Swelling in ankles, feet, legs, abdomen, or veins in the neck	25	15

I felt physically sick, but I couldn't be sick, so I told my wife, something's wrong, you need to take me to the hospital. – Richard, Chicago

You figure if you exercise a whole lot that you don't get much more out of breath than the regular, and it started to occur... so I went to my doctor and he referred me to a cardiologist. – Renee, New York

About 18 months ago, I had some symptoms, and I have a genetic history of high cholesterol - it's just a genetic thing - but coupled with that history along with the symptoms I did a battery of tests…I could be sitting in a chair and not be able to get enough air. You know, there's no stress, there's nothing going on, even though I have an intense job - but there are just times I'm just sitting there watching a movie, and I couldn't get deep enough breaths- it just didn't make sense. And having an active lifestyle you can really see the change - like you work out, I try to too, and I just can't do the things that I used to. – Diane, New York

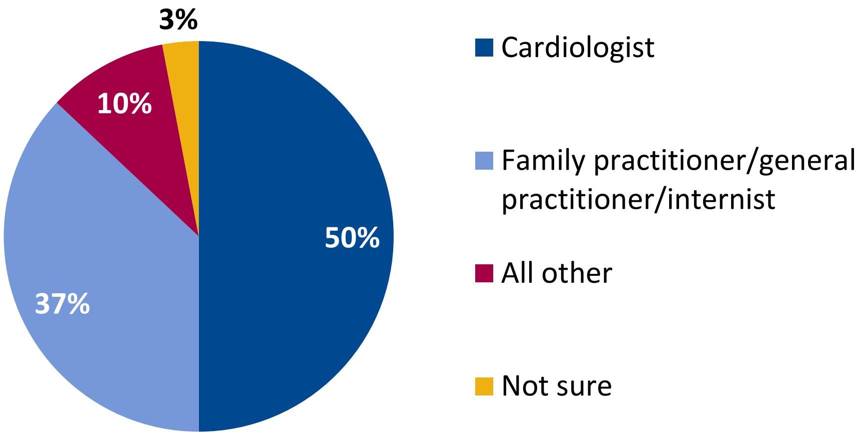
D. Health care professionals involved

The patients in our survey report that cardiologists – and to a smaller degree their “regular” doctors – have been the main sources of diagnosis and ongoing treatment. In addition, cardiologists appear to be providing the most information to these patients and to be central to their decision-making about treatment than other figures.

Starting with diagnosis, half (50%) identify cardiologists and 37% mention physicians such as family practitioners, general practitioners, and internists as the HCP who provided the news. Very small numbers identified other providers such as emergency room or nursing staff.

Healthcare Professional Who Diagnosed Valve Disease

Among Heart Valve Disease Patients



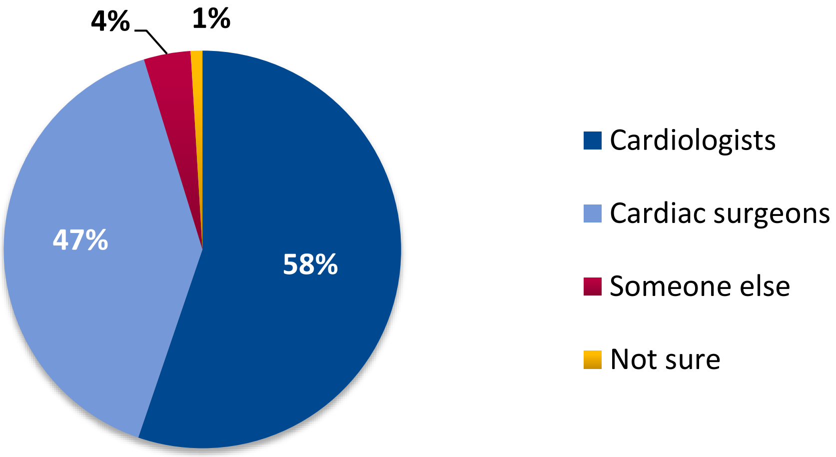
Q11. Which kind of healthcare professional was the first to diagnose your valve disease?

Half the patients (46%) in our survey were referred to some other HCP after their diagnosis. Getting referred is more common among people with incomes over $100,000 (44%), as compared to those with incomes under $50,000 (13%) and between $50,000 and $100,000 (24%). Also referrals are most common for younger patients (49% for those under 55) who also tend to have serious HVD – as compared to those over age 65 (12%) or ages 55 to 64 (13%).

Two thirds of the referrals (58%) went to cardiologists and 47% to cardiac surgeons as well. A quarter (24%) sought second opinions.

Types of Providers Who Were Referrals

Among Heart Valve Patients Who Were Referred



Q12b. [IF REFERRED] What kind of healthcare professional was that? (N=211)

When deciding on treatment, once again we see cardiologists and cardiac surgeons as the most important sources of help. These physicians were cited by six in ten (59%) of the patients in our survey as among the individuals who helped them decide about their valve disease treatment.

However, nearly half (47%) also indicate that other medical doctors, including family practitioners, internists, and GPs, aided them in their decisions. Men, upper income people, and those with high levels of education were the most likely to have had an internist, FP or GP help decide on treatment.

Family, friends, and/or caregivers are mentioned by far fewer as having contributed to their decision making (14%). In the focus groups, on the other hand, participants talked about the importance of family, not only in decision making but in feeling supported. Still, they often lamented family members' incapacity to provide a lot of help.

> I had the support of my family. I was 19, so whatever my parents thought was best, that's what I did. – Jorge, Chicago

> It has a lot to do if you have a bit of family. I have two grown sons and me, it's just the three of us. And not having a female in the family, that makes a big difference too, because men just think different. ..they care, obviously, but it makes it harder when you don't have that. If you have a bigger family, it's so much easier. –Georgia, Chicago
>
> Your family really doesn't know how to react what happened to you; it's not that they don't care. – Jeff, Chicago

In the survey, nurses, NPs and PAs were noted by 10%. Support groups helped only a fraction – less than one percent.

Contributors to Deciding Valve Disease Treatment

Q20. Sometimes the decision about how to treat a specific illness involves more than one person. Which if any of the following have helped you decide about your valve disease treatment?	
Cardiologist and/or cardiac surgeon	59%
Family practitioner, general practitioner, or internist	47
Caregiver, family member, or friend	14
Nurse practitioner, nurse, or physician's assistant	10
Geriatrician	4
A support group	*
No one else, just me	12
Not sure	2

However, as we report later, nurses, NPs and PAs have an important role for some patients in providing much-appreciated education about HVD – even if the medical doctor gets recognition for guiding patients in making decisions.

E. Barriers to care

Among the barriers to getting the care they need that our respondents have encountered, the biggest difficulty appears to be understanding how to make their way through treatment. A third of the patients in our survey (32%) says simply understanding "how to go about getting treated" has been a problem in getting care. Secondly, a quarter (24%) says it does not have family or friends who "can help me enough."

Other barriers for the patients include: a lack of medical facilities and/or doctors with the expertise near to them (18%); the care is too expensive (17%); and difficulty getting referrals and appointments with experts (16%). Also 14% have had trouble getting their insurance to cover the care.

The youngest patients – those under age 55 – are the most likely to mention difficulties with referrals, insurance, and proximity to services.

Barriers to Needed Care for Heart Valve Disease Patients

Q31. Please indicate which, if any, of the following have been a problem for your getting the care you need for you heart valve disease.

It has been hard for me to understand how to go about getting treated.	32%
I do not have family members or friends that can help me enough.	24
There are not enough medical facilities and/or doctors with the expertise near where I live.	18
The care is too costly for me.	17
It was or has been difficult to get a referral to and/or appointment with a valve expert.	16
I have had difficulties getting insurance to cover the care.	14

In the focus group discussions, we did not hear many complaints about barriers to treatment, possibly because the group members were also individuals who had a confirmed diagnosis of HVD – in other words, they had the resources to get a diagnosis in the first place. Rather than talk about financial or other barriers, some of the participants said their own reluctance or lassitude prevented them from confronting their disease and dealing with it.

> I guess when things are going good, you think you're fixed. – Jeff, Chicago

F. Getting treatment

Providers: When it comes to ongoing treatment, 43% report seeing a cardiologist (not surgeon) for most of their treatments, and 37% see an internist, family, or general practitioner. Just a few (7%) see a cardiac surgeon currently.

Other medical personnel, such as NPs, PAs and nurses provide the ongoing care for 6%.

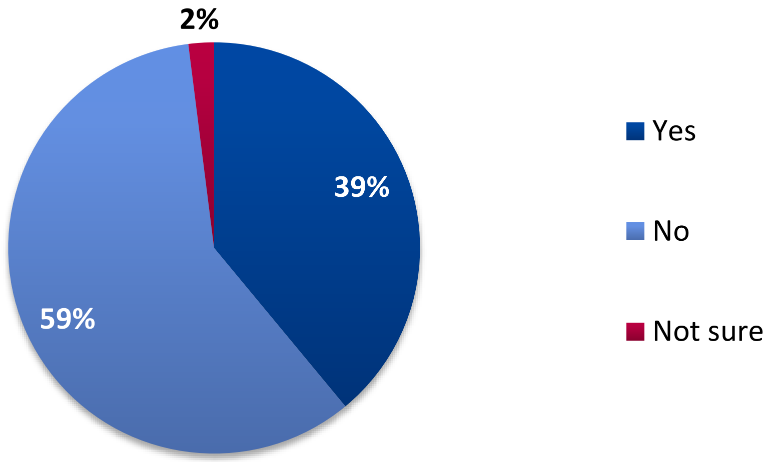
Healthcare Professional Seen Most for Valve Disease Treatment

Q29. Which of the healthcare professionals do you currently see the most for treatment of your valve disease?	
Cardiologist (not surgeon)	43%
Family practitioner/general practitioner/internist	37
Cardiac surgeon	7
Nurse practitioner, nurse, or physician's assistant	6
Geriatrician	*
Emergency department physician	-
Other	4
Not sure	3

Types of treatment: Four in ten (39%) report having been prescribed medication for their valve disease. Men and respondents under age 55 are more likely than others to have been prescribed medication.

Patients Who Have Been Prescribed Medication for Valve Disease

Among Heart Valve Disease Patients



Q14. Have you been prescribed medication for your valve disease?

Over four in ten patients report receiving treatment beyond medicine for their valve disease. Overall, three in ten patients have had full sternotomy or open valve replacement (19%) or valve repair – full sternotomy (12%) surgery. Others have had minimally invasive valve repair (9%) or replacement (6%).

Overall, 57% have had no treatment beyond medicine, but this varies widely by the seriousness of the disease. Eighty one percent of those who only have MVR have had no treatment aside from medication, compared to 41% of those with more serious disease.

Non-Medicinal Valve Disease Treatments

Q15. Aside from medication, which if any of these treatments have you had for your valve disease?

	All	Serious HVD	MVR Only
Valve replacement surgery (full sternotomy or open)	19%	27%	9%
Valve repair (full sternotomy or open)	12	15	8
Valve repair (minimally invasive)	9	14	3
Valve replacement surgery (minimally invasive)	6	10	*
Trans catheter aortic valve replacement (non-invasive) procedure	3	5	*
Robotic procedure	3	5	*
Balloon valvuloplasty	2	3	*
Ross procedure	1	1	*
Something else	4	5	3
No treatment	57	41	81
Not sure	3	5	1

Almost all of those who report that they have not had treatment other than medication say the reason for not seeking more treatment is their “disease is not serious enough to need treatment at this point” (87%). Very few are put off by the expense (4%). Small numbers have been told it is too risky (3%) or they are too old/frail (2%) – or themselves feel the benefits do not outweigh the risks (3%). Fear plays a part for only 2%; and 3% say they are waiting for a less invasive procedure to become available to them.

The focus group participants talked about their reluctance to have surgery.

> I’m just apprehensive about going through different types of surgery - with three children I had Caesareans, and I don’t do well… my whole body shuts down...I know eventually I’m going to have to. – Heather, New York
>
> They’d like to do a valve replacement. I’m not going to do it until I really need it, because right now it’s mild. – Angela, New York
>
> My cardiologist has me do an echo every summer, and he says each summer “get ready for surgery, because next summer we’re going to get in to take care of that, I don’t know why we’re waiting.” I’m considered moderate to severe, but I’m right on the edge, I guess which means the point where you require surgery. I’m not excited about it, I don’t feel the valve is causing shortness of breath, I feel it’s respiratory…They haven’t proven to me that it’s necessary to do… – Alan, Chicago

Ongoing care: In the focus groups the participants told us about their follow up care and instructions. Several talked about the importance of rehabilitation.

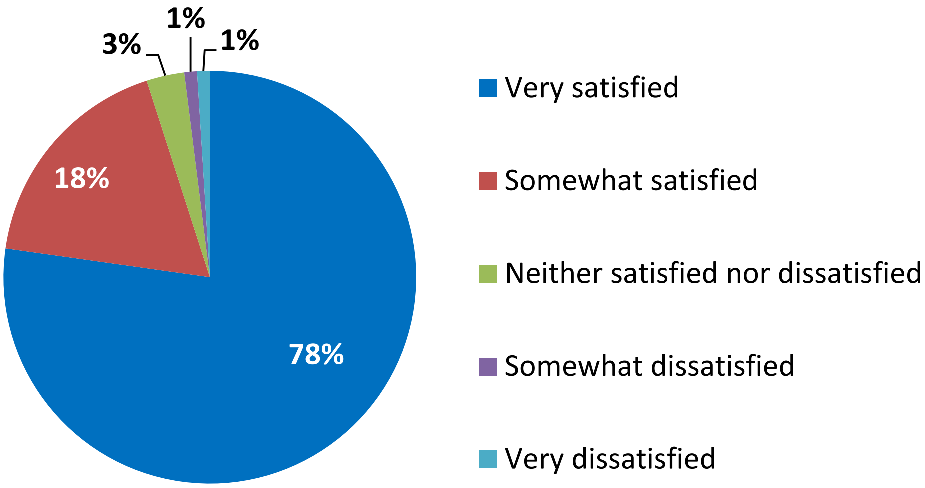
> Rehab for me was probably the key … That got me a good start...The rehab was really key, because it got me on a good diet and exercise routine, and it got my energy that I had back. – Jeff, Chicago
>
> Rehab is key – though in my case I just had to go slowly. – Michael, Chicago

G. Satisfaction

Among those who have been treated (beyond medication), a full 96% express satisfaction – including 78% who are *very* satisfied. This level of satisfaction does not drop below 70% in any demographic subgroup.

Satisfaction with Treatment

Among Heart Valve Disease Patients Who Have Received Treatment



Q17. How satisfied are you with the treatment that you have received for your valve disease? (N=187)

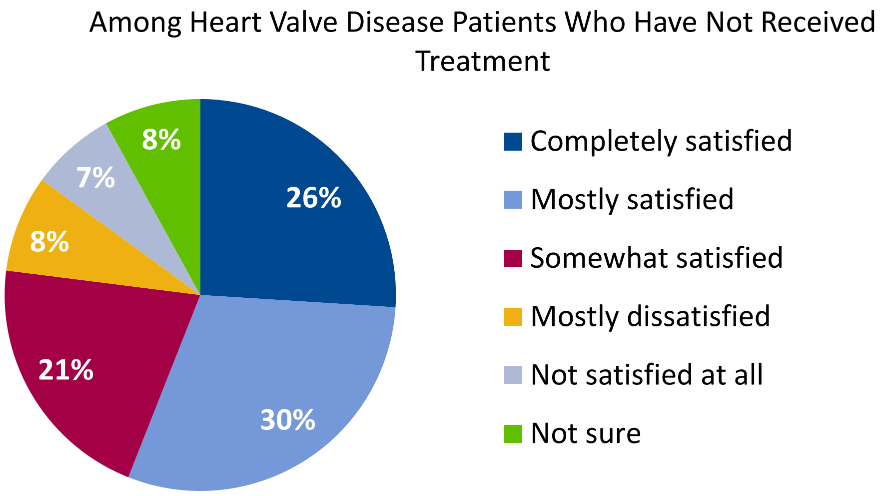
In the focus groups the participants who discussed how satisfied they are with their treatment to date, expressed a range of feelings.

> Well, it's four years later, and as a matter of fact I was just at the cardiologist a few weeks ago, I'm on Lipitor and low dose aspirin, but right now I'm fine. I'm happy. No complaints. – Jim, Chicago
>
> (I feel it's) somewhat (of a success)…because now I have the leakage. It's always something with this heart. It's "let's see, let's see, let's do this, let's see how this is going to work." But for me it's not working. I mean I'm comfortable for a little bit, but it's just not working, and I don't know what's next. I keep thinking that one day my husband is going to leave and go to work, and he's going to come home and I'm going to be dead. And that's frightening. – Mary, Chicago
>
> Psychologically - there are days when I don't think about it, but when you have a condition, I think it's always in the back of your head, because I have high blood pressure, so it's always in the back of my head...the uncertainty. – Renee, New York

> Well, since I'm still alive, I'd say it's been successful. My asthma, the medicine conflicts with the heart medicine at times, so it took 9 months to find the right recipe for my blood pressure, because I couldn't take the best stuff. – Joanne, Chicago

The individuals in our study who have *not* had treatment other than medication for their valve disease have more lukewarm feelings when asked "if you had to spend the rest of your life with your valve disease the way it is right now, how would you feel about this?" A quarter (26%) says it would be completely satisfied, 30% would be mostly satisfied, for a total of 56% in the fairly happy category. Twenty one percent are in the middle, saying somewhat satisfied, while 15% report being mostly dissatisfied or not satisfied at all.

Feelings about Spending Rest of Life with Valve Disease as it is Currently



Q32. [IF NO TREATMENT] If you had to spend the rest of your life with your valve disease the way it is right now, how would you feel about this? (N=207)

Not surprisingly, those untreated individuals with serious HVD are less content with their condition than those with less serious disease. Among those with serious HVD, 43% say they are mostly or completely satisfied compared with 66% of those with MVR only.

The focus groups gave us the opportunity to hear about some of the emotional impacts of the disease. Those conversations suggest that because HVD is not, by and large, caused by behaviors, some of the patients may be frustrated with the lack of control they have over it, while others are simply resigned to that fact.

Just frustrated - you feel like if you exercise enough, you should be cured. You can't do anything to correct it. I'm still figuring out the treatment for it. But that's not true. It's frustrating. – Jack, New York

I was angry, very angry. I was angry at my doctor. I was not one of those people that goes to the doctor for everything. I was really angry because I felt it should've been discovered earlier, and that I should've been put on the proper medication. – Georgia, Chicago

Mixed emotions. I felt good because it's going to be taken care of - but of course you hear "heart disease" and it's a bit scary. They told me that if I didn't take care of it that it would get much worse. I had two strokes. – William, New York

I was in denial, I was like, oh no - I kept going to the gym and doing all this stuff, and my body was like, "Hello? There's something going on." So like William was saying, it gets to a point where you have to face reality and you can only do so much for yourself. You stay as healthy as you can and I think the mind-body connection is very strong, so you have to be positive and hope things turn out for the best. – Diane, New York

I was mad at myself because I didn't listen, I didn't pay any attention to genetics, until I got older, and I should have, because my dad died at 46. He was standing there one minute, and the next he was on the floor and he was dead. But I was 20 years old, I went on with my life. I went to a physical, they said I had high blood pressure...I was just happy. I didn't go, never thought about it again, until all this came up. So I wasn't mad at my doctor, I was mad at myself. – Michael, Chicago

I was devastated- you know you think about my children [who] are still young…I might have to have a valve replacement, and that surgery is $200,000 and I have to pay at least 20%... that's a lot of money right there. ..If I end up in a nursing home, it's not a good thing. There's no medicine to help treat this… aspirin, blood thinners, blood pressure medications - there's nothing to treat it so far. – Angela, New York

I've had so many things wrong with me at one time - diabetes, stroke, it was a lot of things, but I had heard over the years if you had a heart murmur - I didn't think anything of it - I just refused to think of it. And when I had the heart attack, I couldn't understand why it was me. And I have siblings. Why did it have to be me? Why did all these things have to happen to me? So now I'm just having a whole lot of problems with my heart. We go from one thing, we go to another. I've had the nuclear stress test, I've had the second stent put in, now they're talking about a second surgery. So I just don't know how to feel. I try not to be angry, to keep myself calm. – Mary, Chicago

H. Lifestyle impacts

The survey respondents who have been treated either surgically or with medication were asked to reflect on how much their disease had impacted eight activities before being treated and after. Overall, more than half of all the HVD patients report their lives negatively impacted by their disease, that is, 54% report one or more of the listed activities have been affected. Getting physical exercise tops the list at 35% saying that before they were treated, it was limited quite a bit or moderately, followed by taking care of their home (32%) and going out visiting, shopping, *etc*. (32%). Other areas that were limited include having a sexual relationship (28%), working at a job (28%), sleeping comfortably (27%), taking part in hobbies (26%), driving (22%), and taking care of themselves physically (22%).

Activities Limited Moderately to Quite a Bit By Valve Disease Before and After Treatment Among All Patients

Q22/23 a-i. [IF ON MEDS/GOT TREATMENT] Before / After your valve treatment / starting to take medication / getting treatment/medication, how much did valve disease affect the following aspects of your life? (N=238)

	Before	**After**
	Limited quite a bit/moderately	
One or more aspect (net)	**54%**	**42%**
Getting enough physical exercise	35%	30
Taking care of the inside and/or outside of your home	32	29
Visiting, going to entertainment, shopping or doing other things outside your home	32	22
Having a sexual relationship	28	23
Working at your job	28	25
Sleeping comfortably	27	26
Taking part in your hobbies or other special interests	26	24
Taking care of yourself physically, bathing, etc., by yourself	22	22
Driving	22	22

The improvement in these aspects was moderate, when looking at all the respondents, as can be seen in the second column of the table above. The one area that seems to show the most improvement is doing things outside the home, such as shopping or visiting friends.

Looking exclusively at the respondents who have serious HVD, 63% reported being limited quite a bit or somewhat prior to treatment – a figure that falls to 49% afterward. Specifically, we see a nine point drop with treatment in being able to visit, go to entertainment, shop, and so forth.

Also there is improvement of five percentage points in getting adequate exercise, and a six point drop in those reporting having their sexual relationships limited quite a bit or moderately.

Activities Limited Moderately to Quite a Bit
By Valve Disease Before and After Treatment
Among Patients with Serious HVD

Q22/23 a-i. [ON MEDS/GOT TREATMENT AND HAS SERIOUS NVD] Before / After your valve treatment / starting to take medication / getting treatment/medication, how much did valve disease affect the following aspects of your life? IF (N=191)

	Before	**After**
	Limited quite a bit/ moderately	
One or more aspect (net)	**63%**	**49%**
Getting enough physical exercise	43%	38%
Taking care of the inside and/or outside of your home	38	34
Visiting, going to entertainment, shopping or doing other things outside your home	38	29
Having a sexual relationship	37	31
Working at your job	36	33
Sleeping comfortably	35	32
Taking part in your hobbies or other special interests	34	31
Taking care of yourself physically, bathing, etc., by yourself	30	30
Driving	29	30

The focus group conversations reflected the wide variety of experiences the patients have had, from very minor to serious limitations.

> I'm just so tired, I don't want to move...I have young children; it's very, very hard. I just want to go to sleep. I am exhausted. The future is very tough to think about. – Angela, New York
>
> It's a bipolar life. I don't think about it, and then when I'm doing something, my sister will go, "oh you're out of breath, sit down." I don't think about it, and then someone will bring it to my attention. So there is a limiting factor but it's an unconscious one, but then when it comes up, it's there. – Diane, New York

Out of sight, out of mind. Any kind of physical limitations, I just ignore. Just not going to run a marathon. I try to just live as normally as possible.—Jack, New York

And I have a little one, so just trying to keep up with her growing up and running around, it's hard for me to keep up with her because of all the stuff that I'm taking. But I'm glad I'm around to see her growing up, but I wish the lifestyle was better for me. – Jorge, Chicago

I. Getting informed

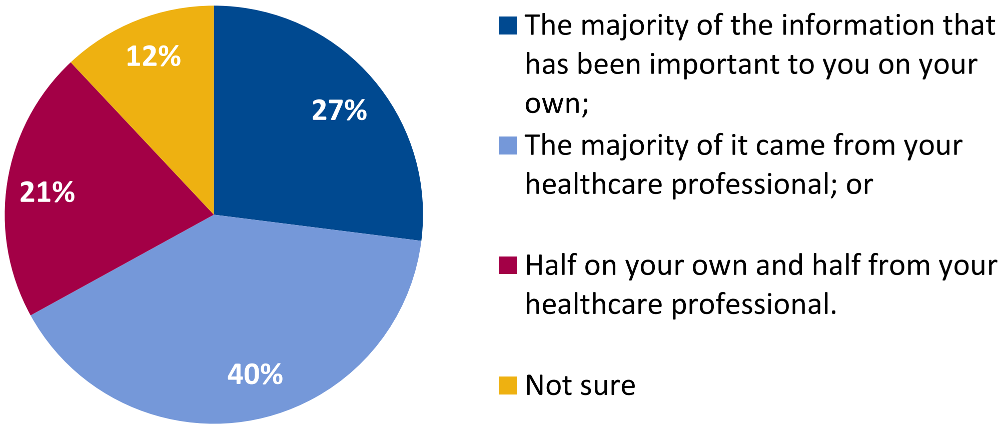
In our focus groups, a number of the participants indicated that they wish they had known more about the symptoms of valve disease earlier, so that they would have known to seek treatment.

> Raising more awareness on valve disease. — Renee, New York
>
> People should have more info about symptoms of various types of heart disease so you could catch them before they happen, genetics, *etc*. – Jim, Chicago
>
> I wish I had warning of upcoming sickness. I wish I had known that a heart attack for me was a probability. I wish I had known the facts of diabetes. – Mary Chicago
>
> I would have liked to know what the symptoms meant. – Bill, New York

Providers as key sources: Now that they are patients with a diagnosis, the individuals in the survey and the focus groups told us they rely on their physicians or other health care providers for the information that matters to them. Forty percent say the majority of the information that has been helpful to them came from their healthcare professional and another 21% say half was from their HCP and half on their own. Less than a third (27%) felt that they found the majority of the important information on their own.

Sources of Information on Heart Valve Disease

Among Heart Valve Disease Patients



Q26. Of the information that you found, would you say that you found: The majority of the information that has been important to you on your own; the majority of it came from your healthcare professional; or half on your own and half from your healthcare professional; or, nor sure.

People with serious disease may be inclined to spend more time searching for information, than are people with less serious disease. Drilling down among patients with serious HVD, 35% say that they obtained the majority of the information that was important to them on their own, and 39% say the majority came from a healthcare professional. Fifteen percent say half was discovered by themselves and half by a HCP. By contrast, 41% of those who have only MVR say that the majority of the helpful information came from their HCP, and only 15% found most of it on their own. Twenty nine percent say half and half.

Those who obtained information on their own tend to be the youngest (57% of those under 55) and most affluent (49% of those with incomes over $100,000), compared to the oldest who relied on the HCP mainly. People with only a high school education and those with incomes under $50,000 said the majority of the important information came from HCPs (47% and 46% respectively).

In person consultation: HCPs appear to disseminate information about valve disease largely in traditional in-person visits. Eighty two percent of the respondents indicated office visits as the way their HCPs most often communicate with them. This rises to 97% – nearly universal – among those over age 65. While other forms of contact are less common ways HCPs communicate with their patients, portals such as My Chart are beginning to register (17% in this study). This is followed by phone calls (15%) and email (12%).

Patients under 55 are likely to be relying less than other people on office visits (58%), and more on a mix of email, telephone, text, video chat, US mail and patient portals.

Methods of Communication with Healthcare Professional

Q30. How does the health care professional that you most often see for valve disease communicate with you?

During in-person visits	82%
Patient portal/My Chart	17
Phone calls	15
E-mail	12
Text	6
Postal mail	6
Video chat	5
Some other way	2
Not sure	4

One participant in New York underscored the value of the information obtained from talking to a physician, saying the one thing she would really like is more time with the doctor and more explanation.

> When the diagnosis comes, I'd like a longer consult. I'd like to see my X-ray. I need to see stuff, I'm a tangible person. What's it supposed to look like? How much more time, or what does it look like now? And one of the things I always say to doctors is, talk to me like I'm seven. I don't want you to just spit out what's up here, like this recording, like here it comes, you're the same patient as the other one. I want it to be broken down so the intention is when I leave, I'm not more nervous, I'm more at ease. And sometimes I have more questions when I leave than when I got there. – Diane, New York

In the focus groups nurses and NPs were praised for their important role in on going care, often providing more attention than the physicians. When asked if they are getting all the information they need, several of the Chicago participants indicated that nurses and PAs were the HCPs who in fact gave them what they needed.

> (As far as getting the information I need) Yes, and no, for me. There is also a nurse with my cardiologist, and I like her better, I think she knows more. I ask questions, and she goes into real detail in explaining - she'll look up the charts for me, and do anything and everything, and the doctor, I don't know, they feel that they are… – Georgia, Chicago
>
> I agree, the nurse had more information than [the cardiologist] did. I know what you're saying. –Jim, Chicago
>
> The PA. and usually my primary has one, and I think she knows more than he knows. …The PA does everything, she answers every question. – Mary, Chicago
>
> The cardiologist also saw my brother, and every time, he called me Jack. (also tried to prescribe medical procedures, based on his brother's issues.) – Michael, Chicago
>
> I think you need to go to a doctor that really likes you. My doctor loves me, because I don't pester her, so if I got something, she takes it really seriously. – Joanne, Chicago

Internet: Half of the HVD sufferers in our survey say they have used the Internet to search for information about their disease. The most popular sites among the Internet users are medical advice ones such as WebMD (64%) and those of big institutions such as the Mayo or Cleveland Clinic (53%). About three in ten (28%) note having looked into websites of non-profit or patient organizations such the Alliance for Aging Research and others.

Sources of Information about Valve Disease on the Internet

Q24a. Have you looked for information on valve disease on the Internet?	
Yes	47%
No	50
Not sure	3

Q24b. (IF Q24a=YES) Which of these have you looked into:	(N=237)
Medical websites, such as WebMD	64%
Websites of medical institutions, such as the Mayo Clinic or Cleveland Clinic	53
Other Internet searches using Google, Yahoo, or Bing	32
Websites of non-profit or patient organizations, such as the Alliance for Aging Research, American Heart Association, or HeartValveSurgery.com	28
Online forums, social network discussions, chat rooms	19
Websites of government agencies, such as the National Heart Lung & Blood Institute	18
Medical technology company websites such as Edwards Lifesciences or Medtronic	17
On-line books	13
No, did not use the Internet	*
Not sure	*

The participants in the focus group in New York used Internet searches frequently, including WebMD and PatientsLikeMe.

> I'm good with other parts of the body, but I find it overwhelming, the stuff that you find, online (about cardiac issues). I find that I'm diagnosed with everything - we're our worst diagnosticians. You name the disease, I could have it. I usually don't fall into that trap, but with this cardiac stuff, everything sounds the same to me, so I stopped doing that. – Jack, New York

> I do it after I get the diagnosis from the doctor. I get basic DX from expert and then I'm like, because of the six minute time limit (that the doctor spends with her), I go home and search for information to elaborate on this medical term. You then go back and get it distilled, get it clarified, but that's how I do it. – Diane, New York
>
> After I've heard what it is, I ask the questions that I can, then I go home and (look it up). – Renee, New York

Fewer of the Chicagoans expressed interest in on line resources. However, the few who said they searched for some information on the web mentioned WebMD and the Mayo Clinic sites. We heard also from two men with genetic, life-long conditions and a woman who uses those resources to research prescriptions.

> I use the web a lot to try to see everyone who has my condition, what they're going through. If it's going to get progressively worse or better, I try to just go on the forums and see where people are at, and interact. The web plays a big part in it for me. Medical forums. Looking at information for disease, reading other people's stories of what they went through. And those kinds of things help me maybe anticipate or see where things are going to progress to. – Jorge, Chicago
>
> When I get a new medication I look it up to see what the pros and cons are. If I'm not with it, I won't take it, and I'll go back and say give me something else. Some of the medications really slow me down and I have no interest in anything. So when I go on the web and see what the consequences are, I go back to the doctor. – Mary, Chicago

Other sources: Not surprisingly, the most frequently used sources of information, aside from the Internet, have been health care providers. Half of HVD patients (48%) say they have asked their HCPs for information about valve disease. Aside from those who have read information in print (19% a book, pamphlet or other publications and 17% the newspaper or a magazine), patients have also consulted other people. Most commonly, these include family and friends (22%). Smaller numbers consulted other patients (12%), someone at a non-profit organization (6%) or someone in or using the resources of a local health clinic (6%). Events such as health fairs and support groups have been even less commonly used.

> I spoke to my brothers and sisters before I made my decision. And I had one friend who had open heart surgery, and I talked to him. – Michael, Chicago

Non-Internet Sources of Information about Valve Disease

Q25. Other than on the Internet, have you looked for information about heart valve disease in any of the following ways:

Asking your healthcare professional	48%
Talking to family members and/or friends	22
Reading a book, pamphlet or other publication about valve disease	19
Reading things in the newspaper and/or magazines	17
Talking to other valve disease patients (in person, through e-mail or on-line, or by phone)	12
Talking to someone at a non-profit or patient organization such as the Alliance for Aging Research or American Heart Association	6
Talking to someone in or using the resources of a local health clinic	6
Attending community events/health fairs	5
Taking part in a support group	4
None of these	31
Not sure	1

J. Support

Services: Other than their reliance on their physicians, the patients in the survey have accessed other support services infrequently, and express a minimal level of interest in them. Three quarters (73%) report they have used none of the services we listed, and two thirds (67%) say they would not have used them if they had had access to such help.

Looking at what the respondents did use, the most popular were rehabilitation services (15%). This is followed by medication assistance (9%), and financial assistance programs (8%). A few used support groups: 7% on-line and 5% in person.

Individuals with serious HVD were more likely to obtain assistance from all manner of services and individuals, although 61% still told us they received assistance from none of items we listed. Fully 91% of patients with MVR only said they obtained no help.

Thinking about what they might have liked, 67% of respondents said none of the services we listed would be attractive to them. About one in ten or fewer expresses a desire for any particular one of these services or programs. Almost all the interest comes from patients with serious disease; half of that group say they would have liked help from one of these services. This compares to 88% of individuals with less serious disease who were not interested in any help.

Sources of Help During and After Diagnosis/Treatment

Q27. Have you gotten help from any of the following when going through diagnosis and/or treatment?

Q28. Which of the following would you have liked to use but did not have access to?

	Help received	**Would have liked**
Rehabilitation services	15%	11%
Medication assistance programs	9	9
Financial support programs	8	12
On-line support groups	7	11
In-person support groups	5	10
Other	2	1
No, none of these	73	67