



Opinion Research
Strategic Communication

Selected Highlights from Opinion Research among Heart Valve Disease Patients

Conducted for The Alliance for Aging Research

June 2016

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 highlights come from 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 was 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 the sample for this study. Respondents were contacted and filled out the questionnaire online March 29 to April 7, 2016.

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

Limited awareness of valve disease: More than two thirds of the valve disease patients with a diagnosis of heart valve disease in the 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 that are recognized by patients: 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 – 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

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 this survey, about half of all HVD patients have had some surgery or procedure and four in ten have received medication related 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 (18%); cost of care (17%); difficulty getting referrals and appointments with experts (16%), and difficulty getting insurance to cover care (14%).

Information sources: Half of those surveyed 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.

Little help from services: The individuals in the survey do not appear to be looking for help outside their one-on-one relationships with their health care providers. However, small numbers of the patients did receive help from services such as rehabilitation services (15%), medication assistance programs (9%), financial assistance programs (8%), on-line support groups (7%), or in-person support groups (5%).

Living with limitations because of HVD: Slightly more than half (54%) those surveyed 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).

