

# **FISTULA FIRST: PATIENT PERSPECTIVES**

## **Patient Questionnaire Final Report**

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# Patient Questionnaire Final Report

## Renal Network 11

### July 2007

#### Background

As part of the Fistula First initiative that began in October 2003, Network 11 developed education materials to assist facilities to educate their patients on choosing the best vascular access. In 2005, a patient video *Your access to Success* was distributed to all Network 11 facilities, along with an accompanying poster, brochures, and other materials. In 2006, a questionnaire was developed to ask dialysis patients in Network 11 about their perspective on these education materials, to gain insight about the usefulness of the information, and to determine if additional resources are needed. In the questionnaire, patients were asked about decision-making, educational resources, and personal experiences with choosing a vascular access. (See attachment 1)

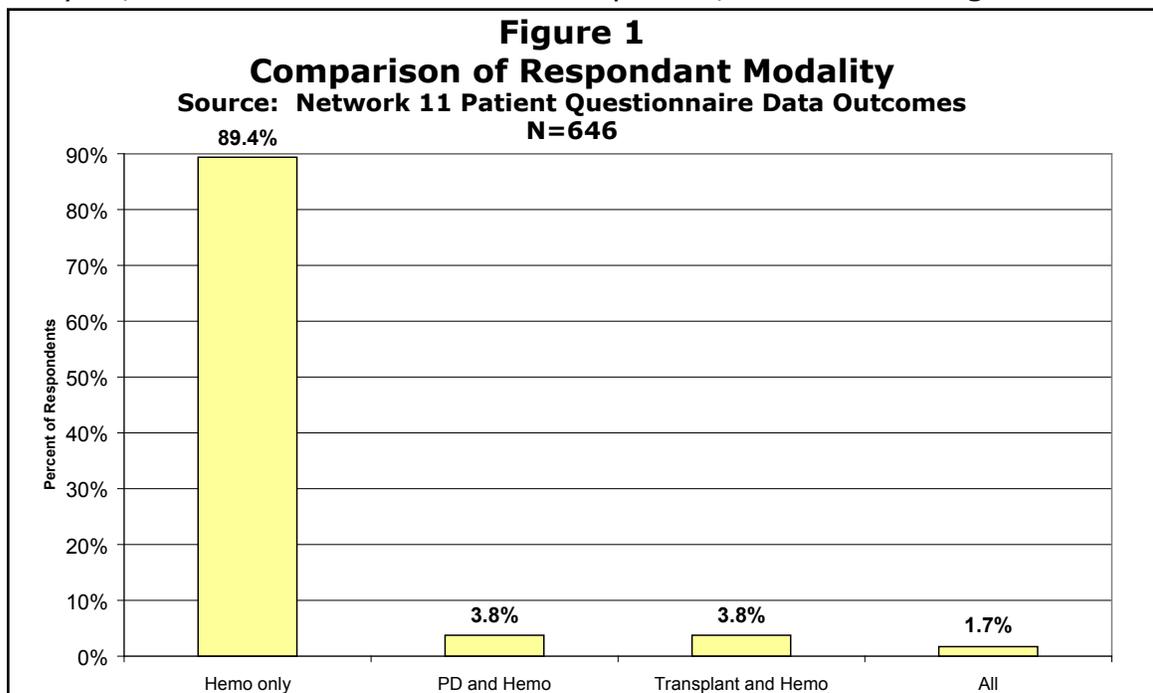
#### Methods

A patient questionnaire was developed in collaboration with Network 11's Consumer Committee and Medical Review Committee. The questionnaire was included in the Fall 2006 edition of the patient newsletter, *Common Concerns*. The newsletters were mailed to all Network 11 dialysis facilities with the request to distribute the newsletter and questionnaire to their patients. Patients were encouraged to complete the questionnaire. The social worker and other facility staff assisted the patients to return completed questionnaires to Network 11 by mail or fax.

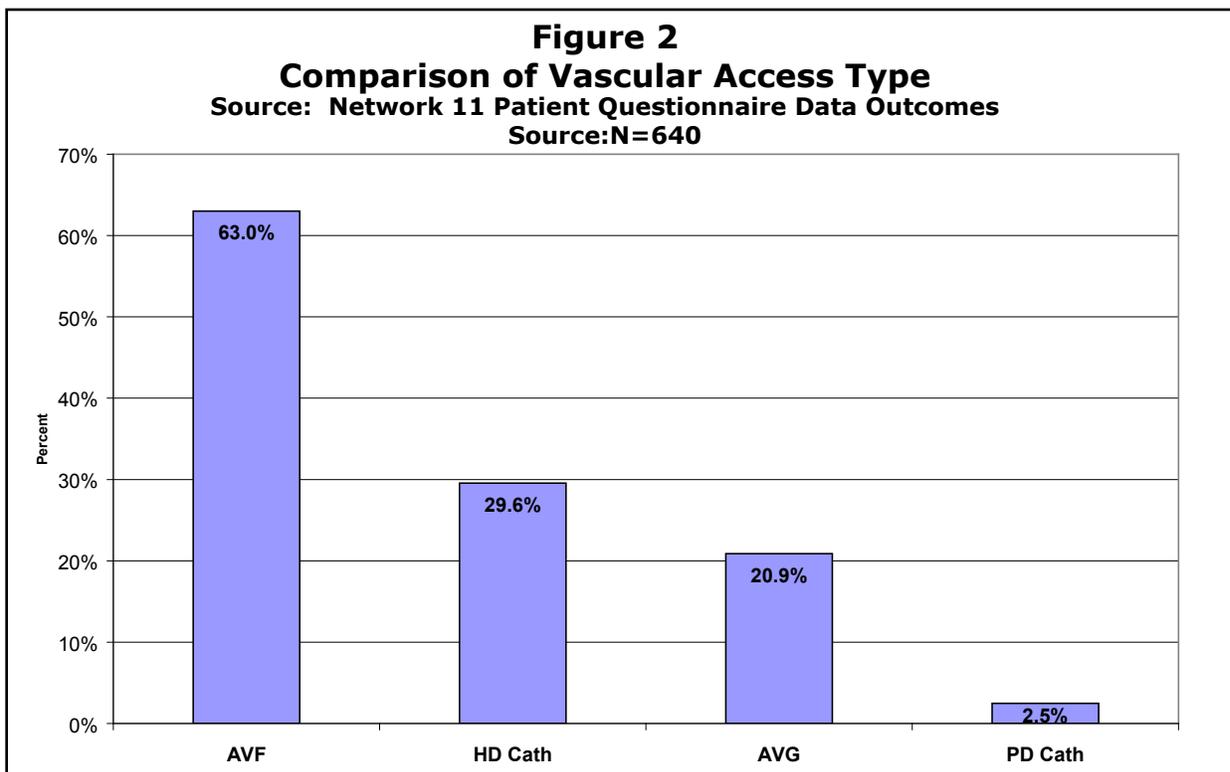
#### Summary of Findings

Network 11 mailed questionnaires to approximately 368 dialysis centers, which reached approximately 21,960 patients. Network 11 received 646 (3%) completed questionnaires. Data was analyzed from the questionnaires received.

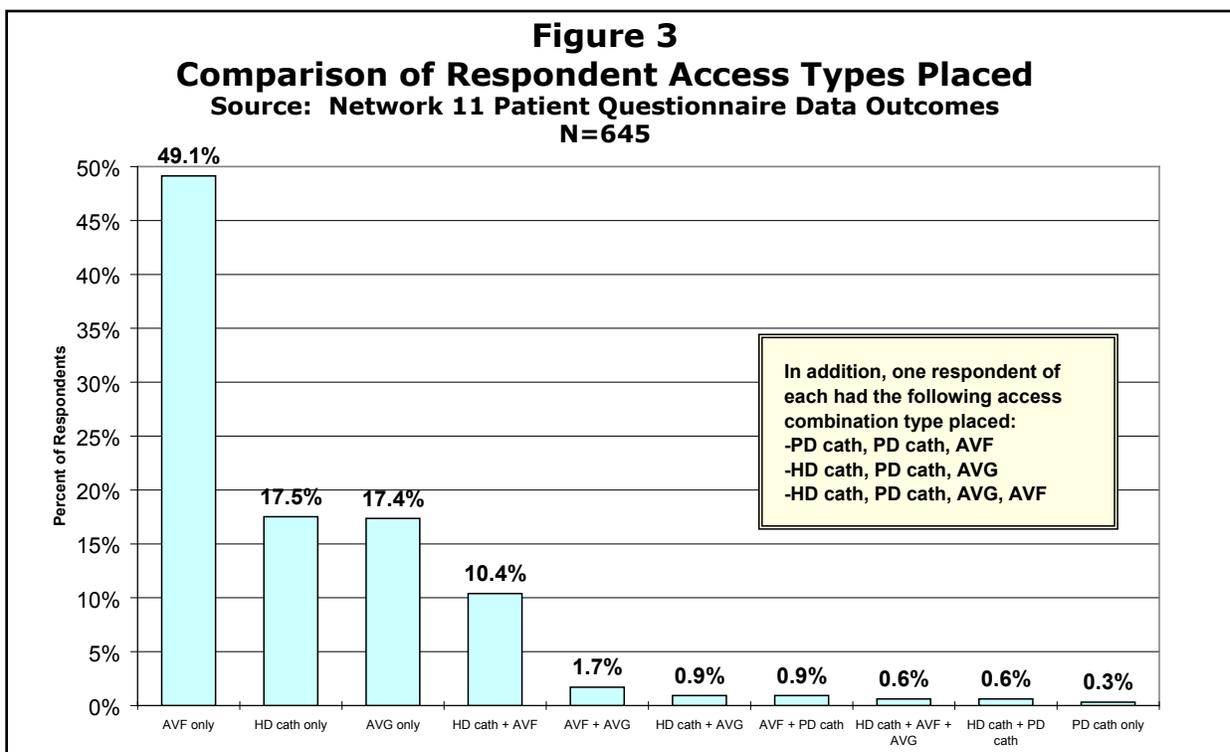
Patient Characteristics: Although the questionnaire was targeted toward patients receiving hemodialysis, other modalities were also reported, as shown in Figure 1. Patients



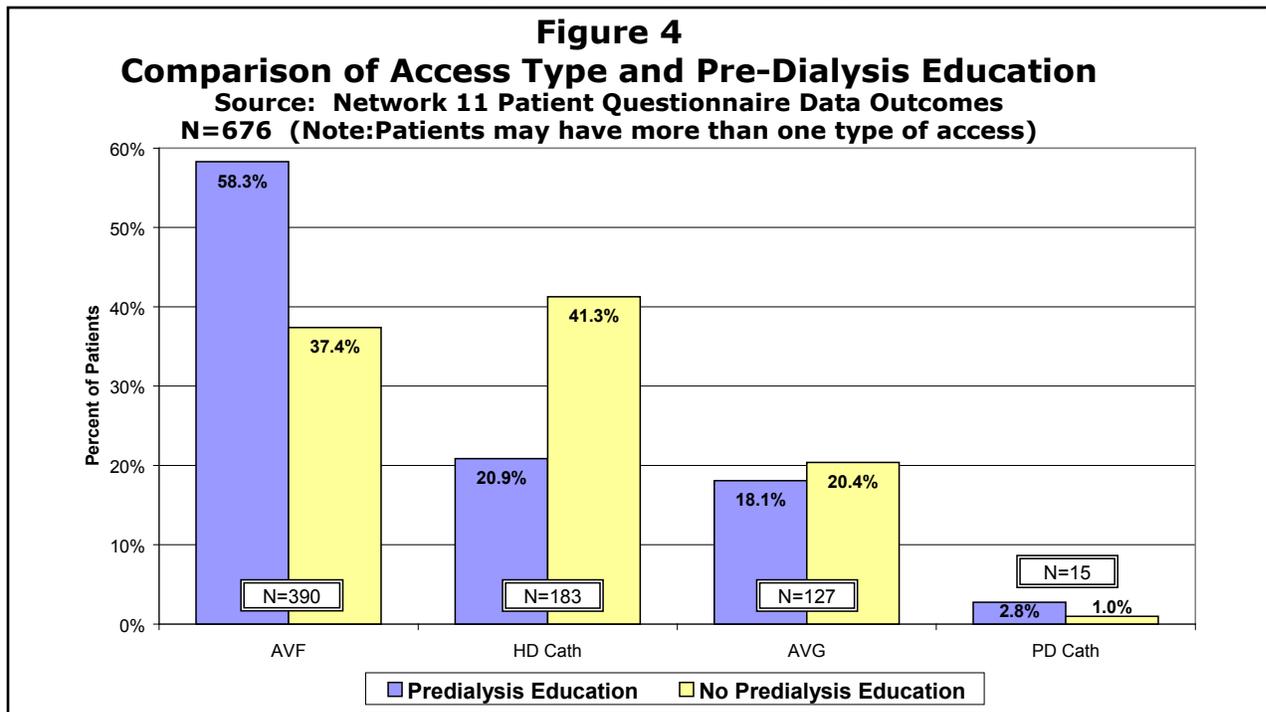
currently receiving hemodialysis were asked the type of dialysis access currently in place. Although there was variation in their responses, the majority (63%) of patients who responded had an arteriovenous (AV) fistula in place. (See Figure 2) In addition,



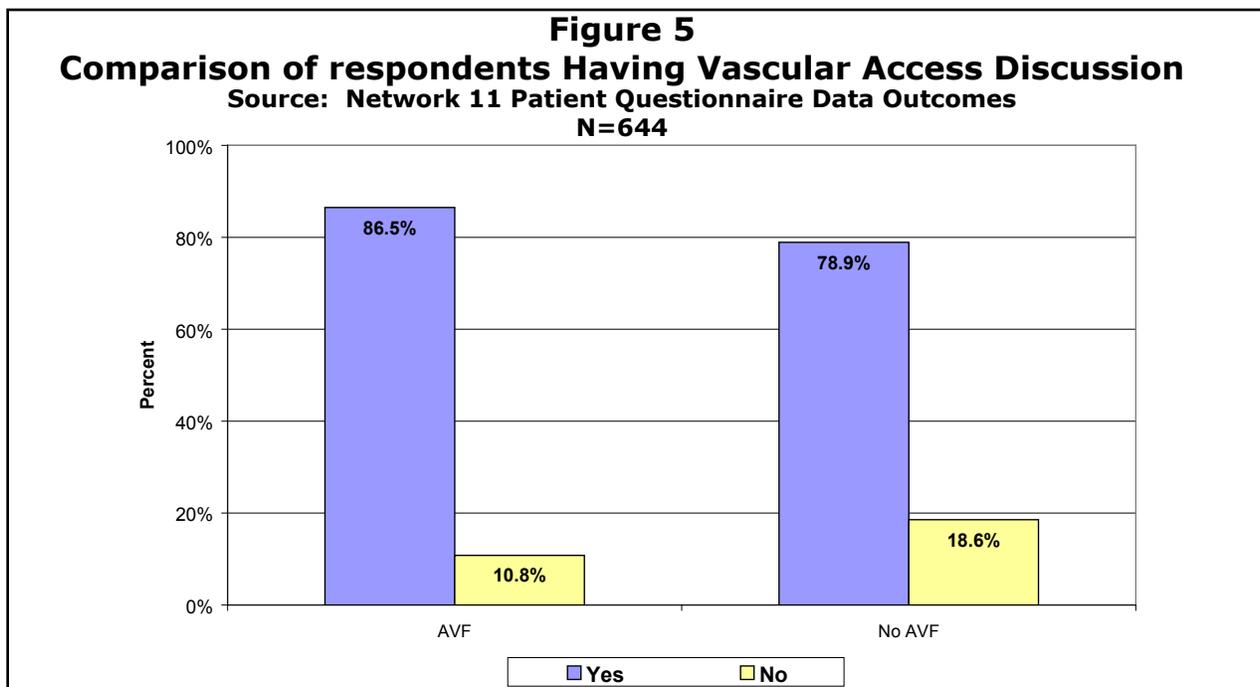
16% of respondents have had more than one access type placed, with some patients having greater than 2 types of access placed, and even one patient who had all four types of access placed, showing great variability among patient experiences in Network 11. See Figure 3.



**Patient Education:** Patients were also asked about the education they received regarding choices in vascular access before and after dialysis was initiated. Two-thirds (66%) of patients confirmed that vascular access education was given prior to beginning dialysis. Figure 4 shows the breakdown of respondents by access type that received pre-dialysis

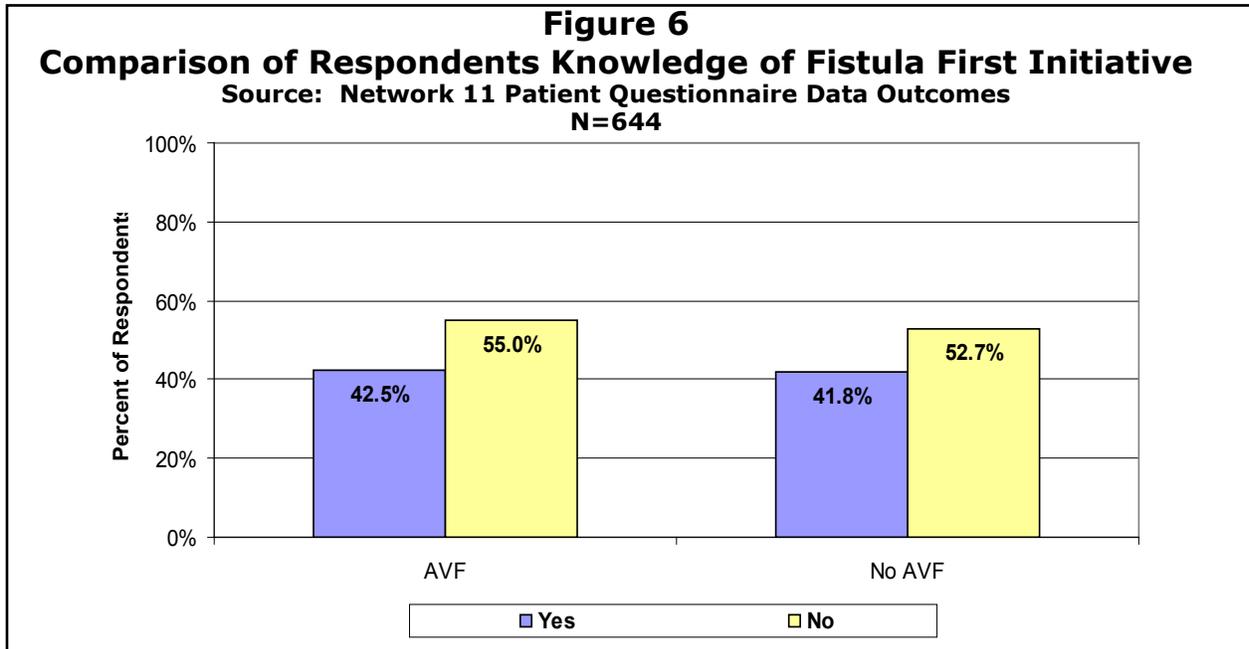


education. Patients who had an AVF were more likely to report receiving pre-dialysis education than patients who did not have an AVF, and people with an HD cath were less likely to report receiving pre-dialysis education than people without an HD cath. Both of these measures were statistically significant with p-value <0.0002. When asked if respondents have had discussions with their nephrologist or facility about the best type of vascular access for them, patients with AVF or non-AVF types report equally that those discussions have taken place, as shown in Figure 5. The majority of respondents (78%)

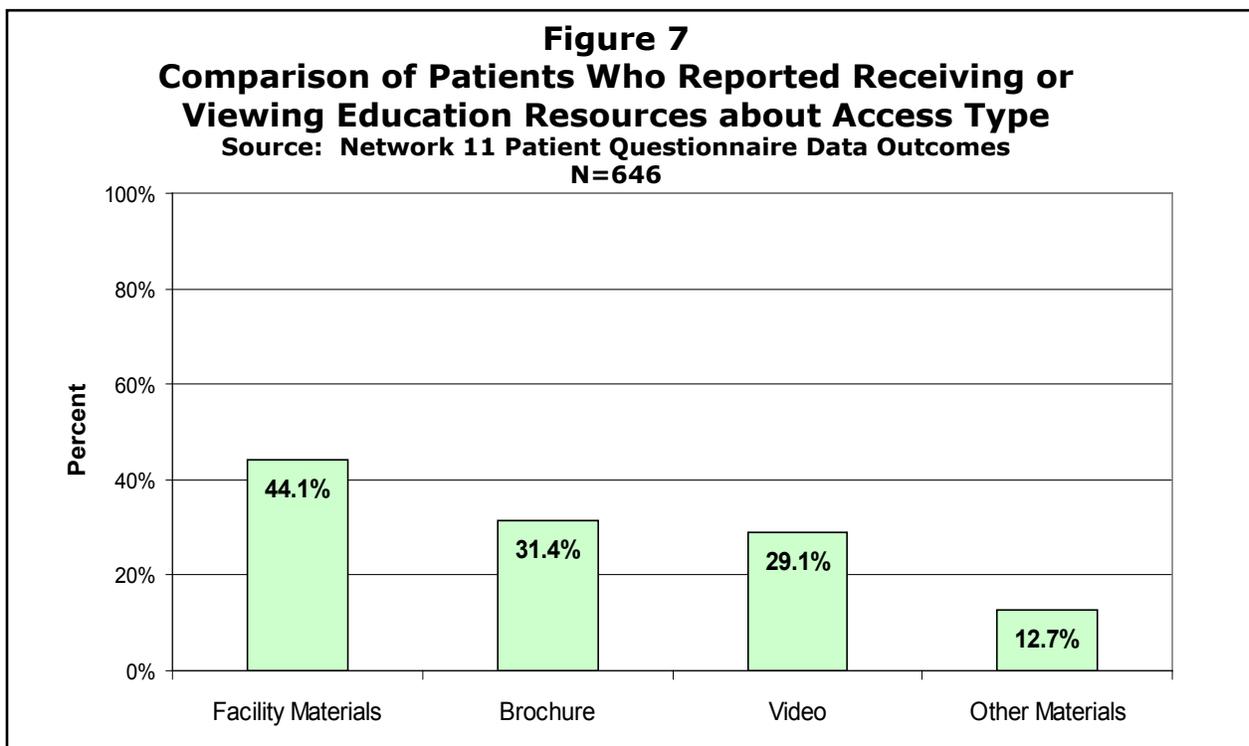


claim to know the differences between a “graft” and a “fistula”, both in the AVF group and in the non-AVF group.

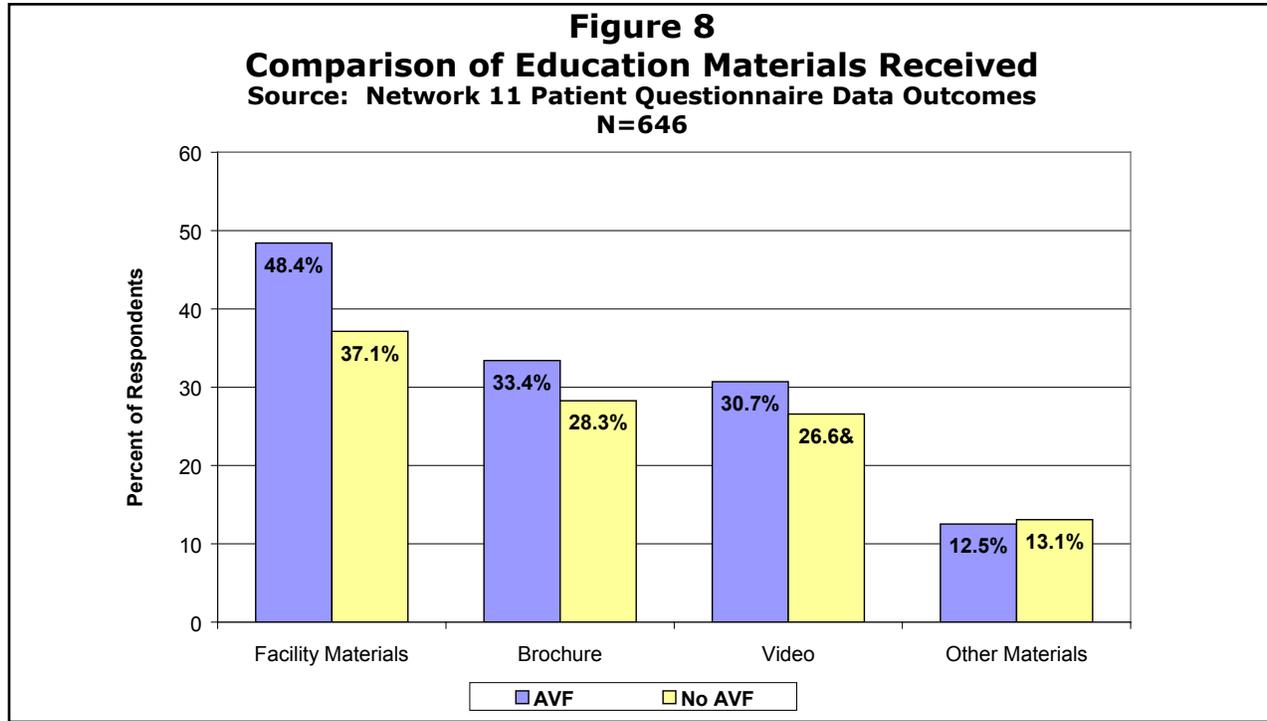
Patient Experiences with Fistula First: While the national Fistula First initiative began over three years ago in October 2003, the majority of respondents indicated they had not heard of Fistula First. This assertion, as shown in Figure 6, was present in both the respondents with an AVF placed and those who did not have an AVF placed. Throughout



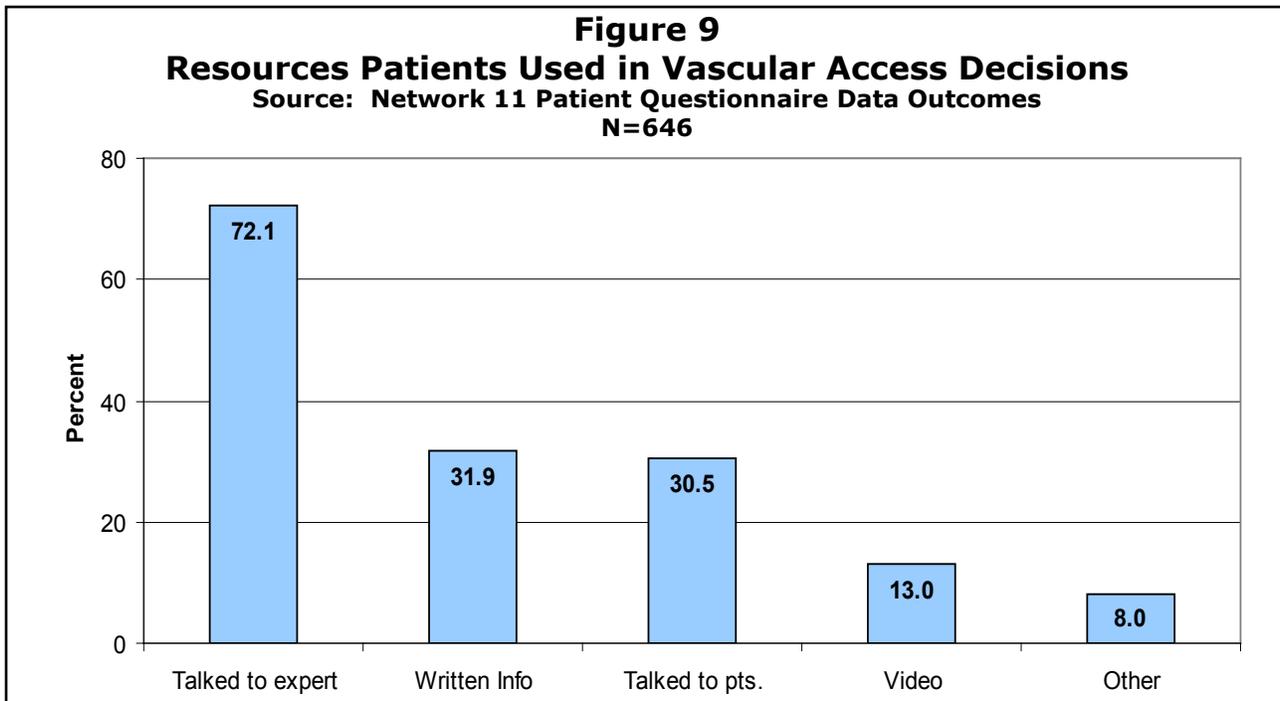
the Fistula First initiative, Network 11 has developed and distributed materials to all Network 11 dialysis facilities. These materials focused on educating patients about vascular access choice. Patients who responded to the questionnaire acknowledged receiving several of these materials, as shown in Figure 7.



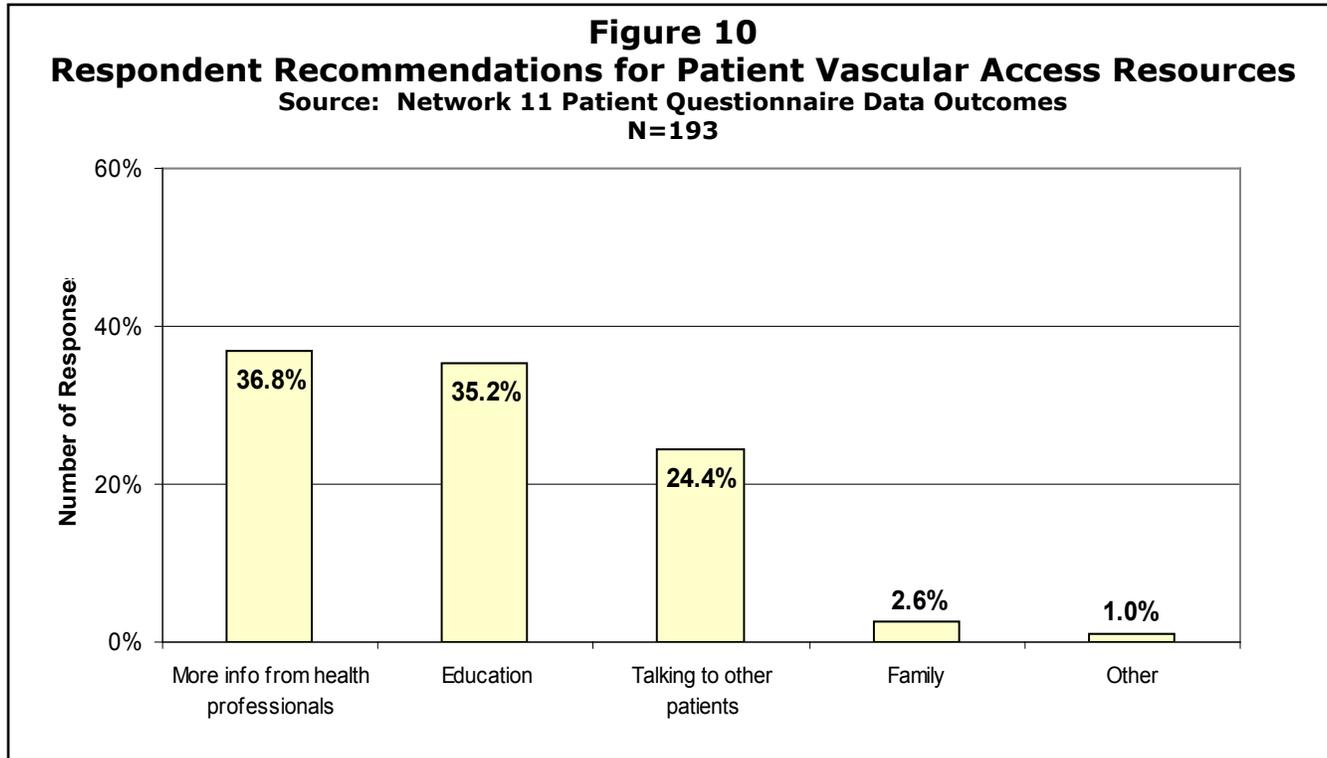
Respondents cite facility materials, the Network 11 *Your Access to Success* video and brochure, along with other materials received but not mentioned by name. Less than half of patients acknowledge receiving materials within their facility, and only 25% of respondents report having seen the Network 11 patient video. While the respondent group having an AVF placed has slightly higher percentages of education material received, both groups have lower than expected percentages of materials received. See Figure 8. Respondents cite different sources as their main resource for making vascu-



lar access decisions, but Figure 9 shows that the majority agreed that talking with their nephrologist or dialysis facility was most helpful. Other resources respondents cited include education literature, talking with other patients, and the patient video. This data



confirms the importance of nephrologists and facility staff talking with patients about the best choices for them when choosing a permanent vascular access. When asked about what additional resources were needed for patients to make the best vascular access decision, respondents recommended that the most important resource is education by nephrologist and facility staff. They also recommended good communication with their family, as well as talking with other patients about their experiences, as shown in Figure 10.



## Conclusion

Network 11 has developed a three-pronged approach to vascular access improvement. This approach includes focus on nephrologist and facility education, surgeon education, and patient education. Perspectives gained from patients are invaluable as new strategies are developed to seek further improvement in AVF placement and use. This patient feedback has shown that opportunities for improvement exist, with 34% of respondents having reported they had not received pre-dialysis education, and many more have not seen patient materials already developed. The association between pre-dialysis education by the nephrologist and the presence of a fistula suggests that pre-dialysis education may be a good area to target for improvement. In addition, the number one patient recommendation of talking with their nephrologist or other health care professional about vascular access decisions also confirms the need to develop strategies to facilitate this communication.

Attachment 1



PATIENT QUESTIONNAIRE

We appreciate you taking the time to respond. Please complete the questionnaire, fold the page, staple and mail to Renal Network 11 or Fax to 651.644.9853.

- 1) What treatment(s) have you received for the loss of your kidney function? (Check all that apply)
2) Which of the following types of dialysis access do you have in place right now? (Check all that apply)
3) Did you receive pre-dialysis education before you began your dialysis treatment?
4) Had you heard of the Fistula First Project before reading this newsletter?
5) Do you know the difference between a fistula and a graft?
6) Which educational resources have you received or viewed about the types of access used for dialysis?
7) If you receive hemodialysis, have you talked with your doctor or facility about which type of access is best for you?
8) Who helped you to decide what type of access to get?
9) What prevents you or has prevented you in the past from getting a fistula?
10) What is the most helpful for you when making decisions?
11) What other resources are needed to help patients make decisions about choosing a dialysis access?