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PHYSICIAN AND PATIENT PERCEPTIONS REGARDING PHYSICIAN TRAINING IN RARE DISEASES: THE NEED FOR STRONGER EDUCATIONAL INITIATIVES FOR PHYSICIANS

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BACKGROUND

Of the ~7000 rare diseases that have been identified, about 25 million patients, or 8% of the population in the United States, is affected.[1] While each disease presents its own clinical challenge to patients, families, and caregivers, one of the common issues is the difficulty in diagnosis.[2] A recent survey of patients and physicians found that it took an average of 5.6 years in the United Kingdom and 7.6 years in the United States to obtain a diagnosis for a rare disease, and most patients needed to provide their health care professionals (HCPs) with information on their rare disease.[3]

Difficulty in diagnosis can be frustrating to patients and HCPs, but can also have serious medical and financial implications. An assessment of the diagnosis of 8 unique rare diseases in Europe found that ~40% of patients surveyed first received an erroneous diagnosis, with some leading to inappropriate medical interventions such as surgery, medication use, or psychiatric intervention.[4] The medical issues related to delayed diagnosis of rare diseases are numerous. For example, in a fatty acid oxidation disorder, the absence of prompt diagnosis and treatment can lead to a metabolic episode resulting in serious, life-threatening complications.[5] In another example, although enzyme replacement therapies are available that prevent disease progression in certain lysosomal storage disorders, delays in diagnosis and treatment can lead to the buildup of cellular byproducts, which significantly affects morbidity and mortality.[6]

There have been a number of initiatives aimed at addressing these issues. The Global Genes Project, one of the leading rare and genetic disease patient advocacy organizations in the world, sponsors grassroots activities to increase awareness internationally.[7] Rare Disease Day is a global initiative aimed at increasing awareness of rare diseases for both HCPs and the population at large[8]; in 2013, representatives from more than 72 countries participated, and in the United States alone, more than 800 patient organizations, government agencies, educational institutions, clinical centers, and corporations signed on as Rare Disease Day Partners.[9] Numerous websites are dedicated to a particular rare disease, and a few use sophisticated algorithms or collective intelligence to aid in the diagnosis of rare diseases.[10,11]

Several rare diseases affecting children are treatable, and with early diagnosis, these treatments can dramatically improve the lives of patients and their families. With this in mind, the Excellence in Pediatrics Institute commenced a rare diseases initiative in 2012 to identify barriers that prevented early treatment.[12] In a survey, 460 pediatricians were asked how closely 14 statements matched their view of rare diseases.[13] The statement "Rare diseases are progressive, so early diagnosis is important" scored 4.4 on a 5-point scale, and the physicians further responded that there were tools that would be helpful to them in their work with these patients.

Despite the recognition that early diagnosis is important, the training of primary care physicians (pediatricians, family practitioners, and general practitioners) has been greatly overlooked in discussions concerning the diagnosis of rare diseases. We conducted a survey of patients with rare diseases and their parents/spouses, physicians, and allied HCPs to determine the extent and perceptions of physician training regarding rare diseases.

METHODS

An invitation to participate in an online survey was sent to physicians and allied HCPs by e-mail. The invitation was also sent to patient organizations, which in turn posted the survey link on their websites or sent it in their newsletters or other communications to patients and families affected by rare diseases. The survey was

conducted with a standardized questionnaire that was published on a secure site and housed on a dedicated server to ensure patient confidentiality. The survey was available from August 2012 to August 2013, and invitations to participate were sent to potential participants a number of times during the year using different deployment lists.

A total of 837 patients, parents, and spouses and 531 HCPs participated in the survey. Of these, there were 805 patients, parents, and spouses and 367 HCPs who provided evaluable data. Data were provided for 920 patients; if parents noted that "I am a parent of more than one child with a rare disease," it was assumed that they had 2 children they were reporting on, and all analyses were conducted using this assumption. Data were considered evaluable if respondents gave their permission for their responses to be used, and if they provided information about their rare disease experience as well as their thoughts about physician education in rare diseases.

RESULTS

Demographics

Data were evaluated for 920 patients and 367 HCPs. The HCPs represented 13 countries and patients represented 26 countries; most respondents were from the United States (**Table 1**).

HCPs included physicians (340), nurses (10), genetic counselors (3), a physician assistant, a pharmacist, and a kinesthesiologist. Eleven respondents did not provide their professional designation. HCPs had been in practice an average of 19.3 years (range, 1–54 years) and most were associated with a private group-practice setting or academic teaching institution (**Table 2**). Of the 41 who practiced in settings characterized by "Other," they included federally funded clinics, public health departments, nonprofits, correctional facilities, habilitation clinics, and university health services.

There was a fairly even gender distribution among the HCPs, with 197 responses from women (54%) and 170 from men (46%). For patients, the respondents were much more likely to be female (88%) than male (12%).

For the patient respondents, nearly 87% were patients with a rare disease or the parent of one child with a rare disease. The respondents included those who were patients (344), parent of one child with a rare

Table 1. Geographic Distribution of Survey Participants

Health Care Providers		
Country	**Number of Providers**	**%**
Argentina	1	0.3
Australia	1	0.3
Canada	4	1.1
Germany	1	0.3
Greece	1	0.3
Hungary	1	0.3
New Zealand	1	0.3
Norway	1	0.3
UK	1	0.3
USA	344	93.7
Unknown	11	3.0
Health Care Provider Total	**367**	**100.0**

Patients		
Country	**Number of Patients**	**%**
Argentina	1	0.1
Australia	23	2.5
Austria	1	0.1
Bosnia	1	0.1
Brazil	1	0.1
Bulgaria	1	0.1
Canada	166	18.0
Finland	1	0.1
Germany	1	0.1
India	4	0.4
Iran	1	0.1
Ireland	5	0.5
Japan	1	0.1
Libya	1	0.1
Mexico	5	0.5
New Zealand	10	1.1
Poland	2	0.2
Saudi Arabia	1	0.1
Spain	3	0.3
Sweden	1	0.1
Trinidad	1	0.1
Turkey	2	0.2
UK	29	3.1
USA	658	71.5
Patient Total	**920**	**100.0**

Table 2. Practice Setting of HCPs

Setting	Solo Private Practice	Group Private Practice	Academic Teaching Institution	HMO, Corporate or Hospital Owned Practice	Other
No. of responses	44	135	116	30	41
% responses	12	37	32	8	11

Table 3. HCP Specialties

	Specialty	No. (%)	Pediatric Focus, No. (%)
Specialists 116 (31%)	Allergy	1 (0)	2 (1)
	Cardiology	5 (1)	6 (2)
	Dermatology	3 (1)	2 (1)
	Emergency medicine	3 (1)	0 (0)
	Endocrinology	1 (0)	6 (2)
	Genetics	5 (1)	11 (3)
	Hematology-Oncology	0 (0)	3 (1)
	Neonatology	9 (2)	n/a
	Nephrology	2 (1)	1 (0)
	Neurology	3 (1)	5 (1)
	Ophthalmology	1 (0)	0 (0)
	Orthopedics	1 (0)	3 (1)
	Physical medicine	2 (1)	1 (0)
	Pulmonology	2 (1)	2 (1)
	Rheumatology	3 (1)	0 (0)
	Other	15 (4)	18(5)
Primary care 253 (69%)	Family practice	53 (14)	11 (3)
	General practice	6 (2)	5 (1)
	Internal medicine	8 (2)	8 (2)
	Pediatrics	162 (44)	n/a

disease (355), patient and parent of one child with a rare disease (32), parent of more than one child with a rare disease (49), patient and parent of more than one child with a rare disease (14), spouse of a person with a rare disease (7), spouse and one child has a rare disease (1), spouse and 2 children have a rare disease (2), and patient and spouse of a person with a rare disease (1).

The percentage of patients who were the only person with a rare disease in the immediate family was estimated at 76.7%, 2 patients with a rare disease in the immediate family was estimated to be 18.0%, and at least 3 patients with a rare disease in the family was estimated to be 5.3%. Because patients did not always note if they were the only rare disease patient in the family, it is possible that these estimates over represent families that have only one person affected by a rare disease.

The sample of primary care physicians was well rounded, and the respondents were most often pediatricians or family practitioners (**Table 3**). A number of specialties noted by respondents were categorized as "Other." These included oral maxillofacial pathology (1), hospice/ palliative care (2), infectious disease (2), immunology (2), adolescent medicine (1), developmental pediatrics (2), pediatric urologist (1), pediatric critical care (5), child abuse (1), pediatric gastroenterology (3), dentist (2), neurosurgeon (1), occupational medicine (1), neuromusculoskeletal (1), neurometabolic (1), psychiatry (1), ob/gyn (4), midwife (1), and sexually transmitted diseases (1). Two respondents had dual specialties: one in endocrinology and genetics, and the other in neurology and genetics.

Assessment of HCP Experience

The rare disease experience of HCPs was assessed. Most (74%) currently saw at least one patient with a rare disease, but the specialists were likely to see a larger volume of patients (**Figure 1**). The 246 respondents who were considered primary care physicians saw an average of 12.7 patients with a diagnosed rare disease (range, 0–1000) and had an average of 1.6 additional patients in whom the disease was in the process of being diagnosed (range, 0–47). The 123 respondents who were considered specialists were just as likely to see patients with rare diseases, but they saw more: on average, they saw 201.4 patients who had been diagnosed with a rare disease (range, 0–5000) and 55.0 patients in whom the disease was in the process of being diagnosed (range, 0–1000).

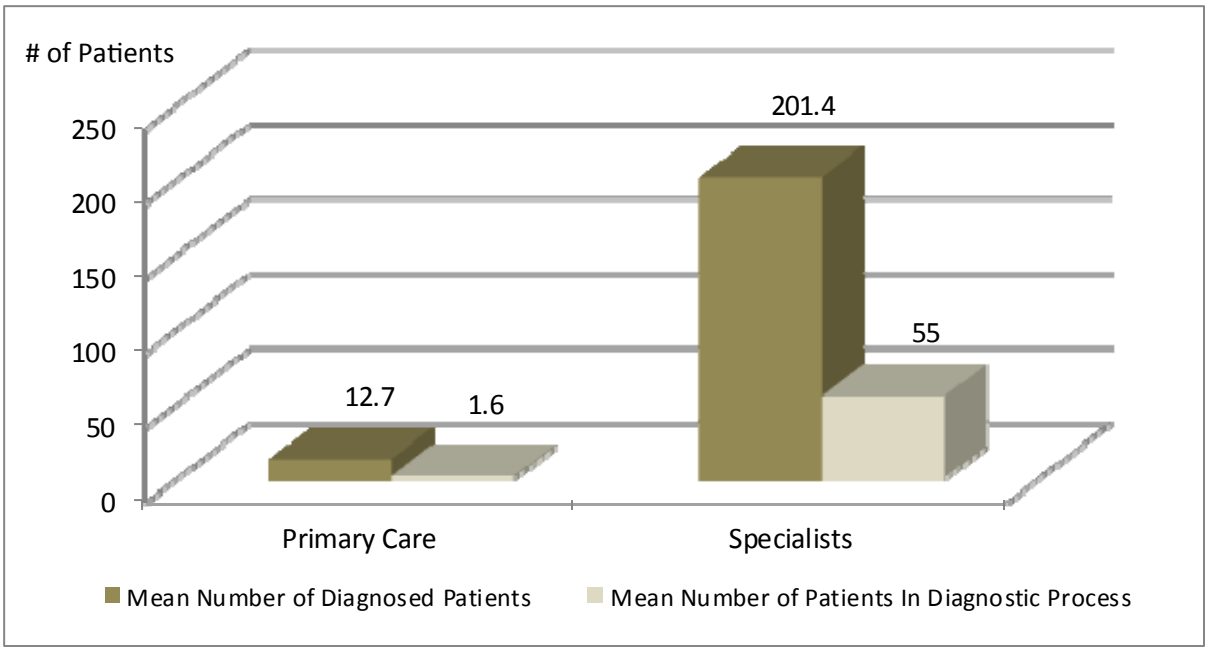

Figure 1. Mean volume of patients seen by primary care or specialist.

The physician respondents reported more than 16,000 living patients who had ~529 different rare diseases. They also reported more than 2000 patients with a rare disease who were deceased and more than 2500 patients who were lost to follow-up.

The respondents were asked about their role in and attitudes about the diagnosis of rare diseases. As shown in **Figure 2**, primary care physicians were more likely to refer the patient to a specialist to make the diagnosis, and specialists were more likely to consult the literature to help them make the diagnosis. Both groups were equally likely to consult someone they considered a "disease expert" to help them make the diagnosis.

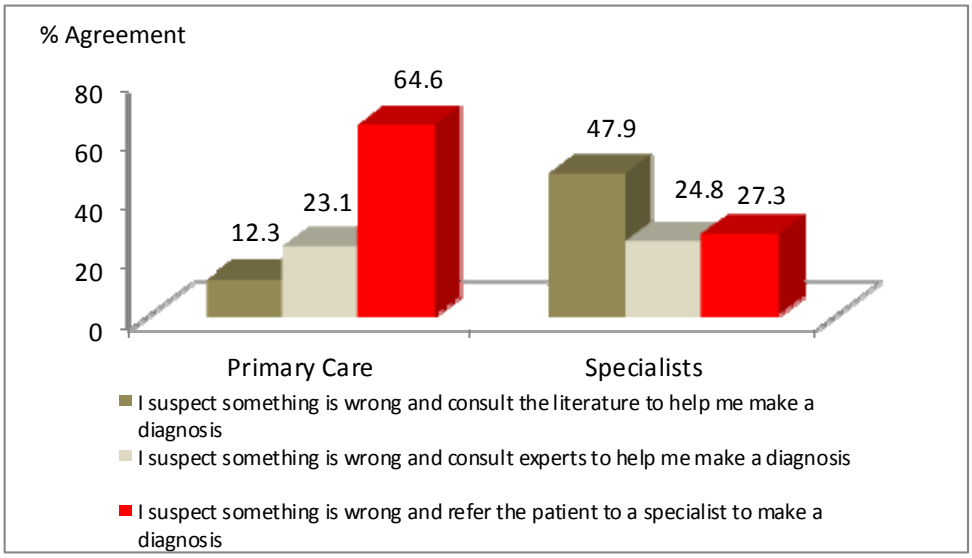

Figure 2. Role in diagnosis of rare disease by primary care or specialist.

To more fully understand the reasons why HCPs relegated themselves to a certain role in the diagnosis of a rare disease, respondents were asked to note their agreement with a series of statements that focused on the number of rare diseases, time allotted with patients, the experience of others, and how diagnosing a rare disease made them feel.

The number of rare diseases appears to have an impact on the willingness of some physicians to get involved in diagnosis. As shown in **Figure 3**, primary care respondents were more likely than specialists to agree with or be neutral about the statement "I can't get involved with the diagnosis of a rare disease, there are just too many of them for me to be aware of." Specialists were most likely to disagree or strongly disagree with the statement.

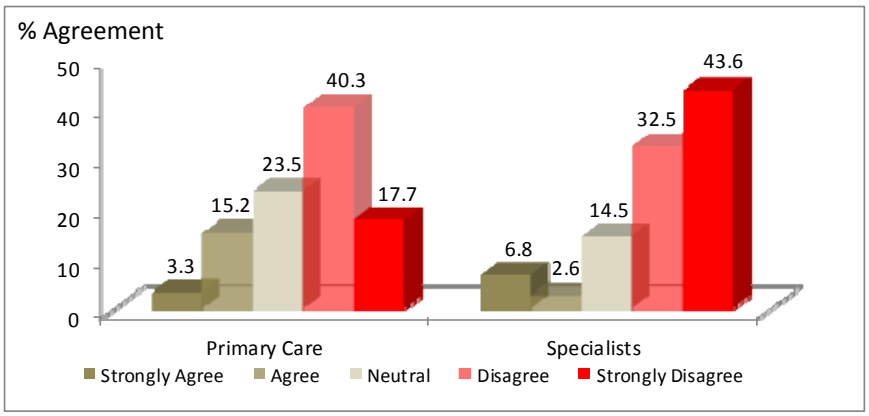

Figure 3. Agreement by primary care or specialist: "*I can't get involved with the diagnosis of a rare disease, there are just too many of them for me to be aware of.*"

The time allotted to see a patient during a medical visit may also have an impact on the diagnosis of rare diseases. As shown in **Figure 4,** primary care respondents were more likely than specialists to see time with a patient as a factor affecting their ability to diagnose a rare disease.

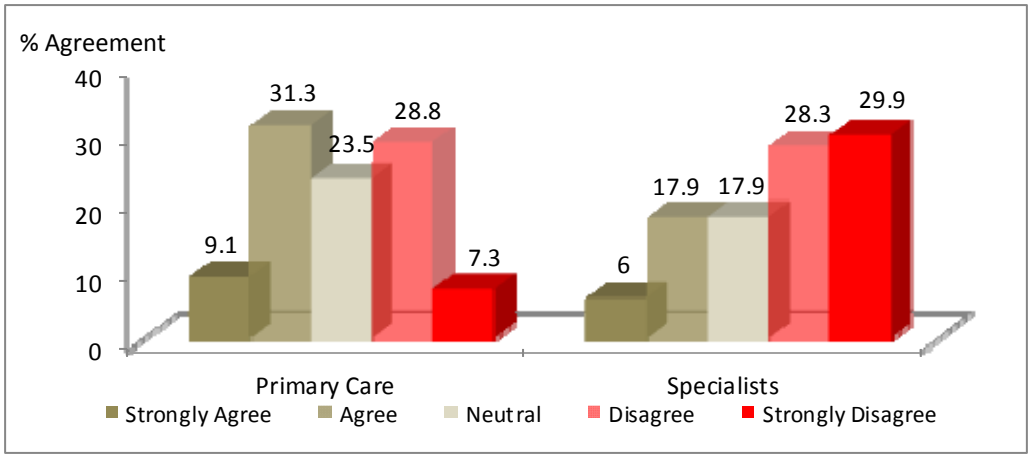

Figure 4. Agreement by primary care or specialist: "*I am not allowed sufficient time with a patient to do a workup for a rare disease even if I suspect one*."

Lack of experience with patients with rare diseases also had an impact on primary care physicians' willingness to be involved in diagnosis. As shown in **Figure 5**, 79% of primary care respondents either strongly agreed or agreed with the statement "Because certain other specialists/experts have more experience, I prefer to refer suspected rare disease patients." Specialists were much less likely to agree with the statement.

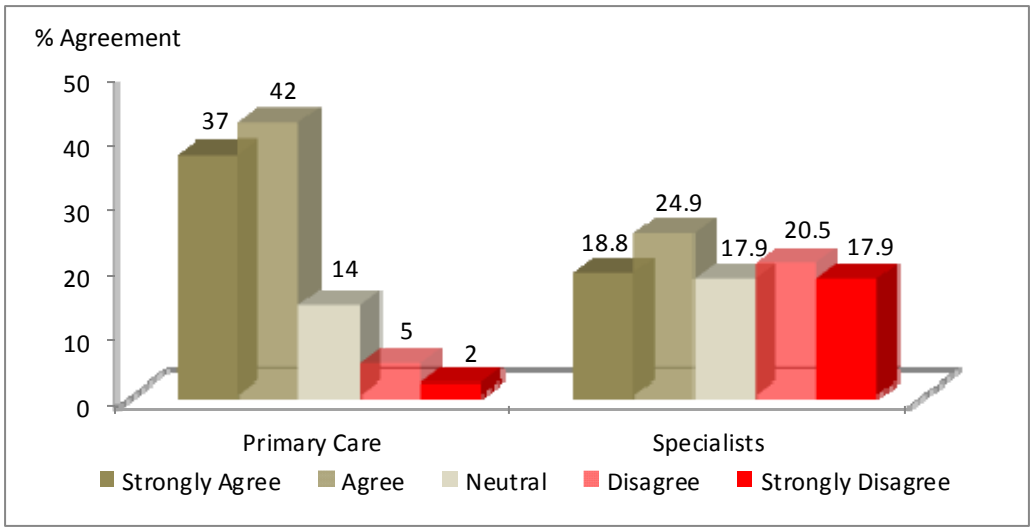

Figure 5. Agreement by primary care or specialist: "*Because certain other specialists/experts have more experience, I prefer to refer suspected rare disease patients*."

Intellectual stimulation and a sense of challenge from diagnosing a rare disease were more frequently reported by specialists than for primary care physicians; 75.2% of specialists and 51.5% of primary care agreed or strongly agreed with the statement "I enjoy diagnosing rare diseases—I like the challenge," and 80.3% of specialists and 60.1% of primary care agreed or strongly agreed with the statement "I enjoy diagnosing rare diseases—the cases are intellectually stimulating."

Beyond the personal satisfaction that might come from diagnosing a rare disease, making a difference in a patient's life also appears to play a role. Respondents were asked to note their level of agreement with the statement "I enjoy diagnosing rare diseases—I feel like I am 'making a difference' for the patient." Most specialists (77.7%) agreed or strongly agreed with this statement, compared with 58.4% of primary care.

Care of a patient with a rare disease requires knowledge of the condition, and many parents report that they often educate their physician about their child's rare disease.[3] Respondents were asked to rate their level of knowledge of the rare disease or diseases that they treat, at the time that the patient was first diagnosed. Those respondents considered primary care physicians were much more likely to rate their level of knowledge as fair or poor (56.4%) compared with respondents who were considered specialists (6.0 %). The level of knowledge increased over time for both groups, with only 18.5% of primary care rating their level of knowledge of the rare disease as excellent or good at the time of diagnosis, and 58.6% rating it excellent or good currently. Specialists also increased their knowledge; however, 59.0% rated their knowledge of the rare disease as excellent or good at the time of diagnosis, and 76.9% rated it as excellent or good currently (**Figure 6**).

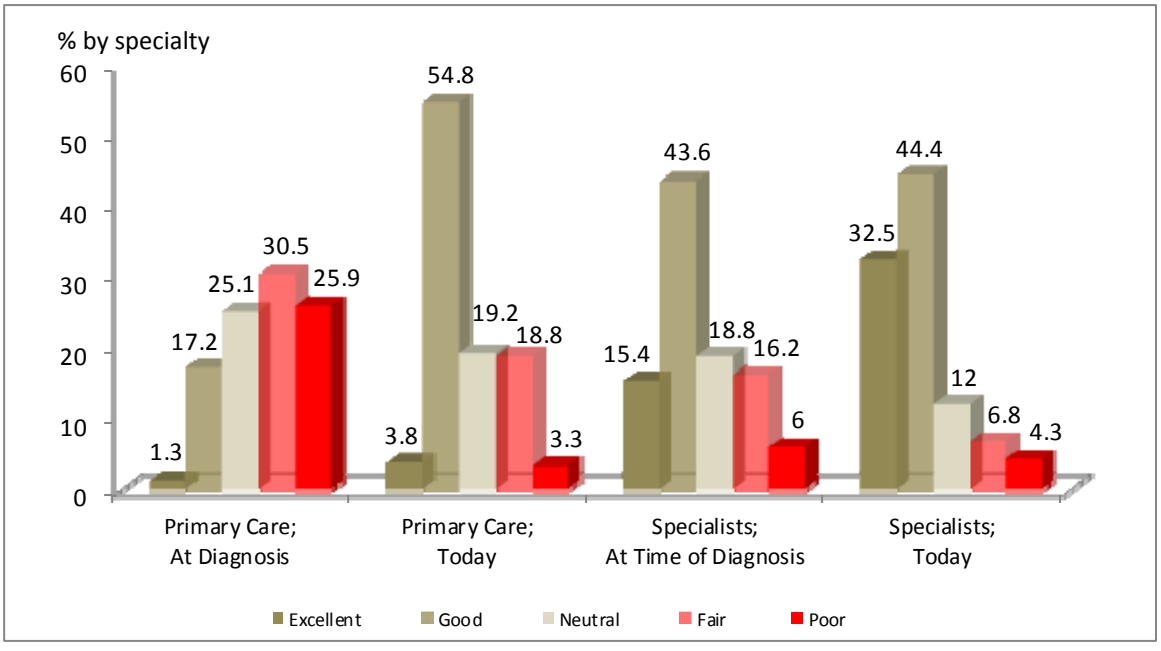

Figure 6. Rating of level of knowledge of rare disease at time of diagnosis and today, by specialty.

Each group of respondents undertook activities to augment their knowledge of rare diseases. The 239 primary care respondents reported 679 activities (mean of 2.8 per respondent) and the 117 specialists reported 422 activities (mean of 3.6 per respondent) that were undertaken to augment their rare disease knowledge. All respondents were most likely to assess the medical literature, discuss the case with local colleagues, and contact local or national experts to obtain advice or guidance; specialists were much more likely than primary care physicians to attend a conference or seminar or contact the National Institutes of Health (NIH) to obtain information (**Figure 7**).

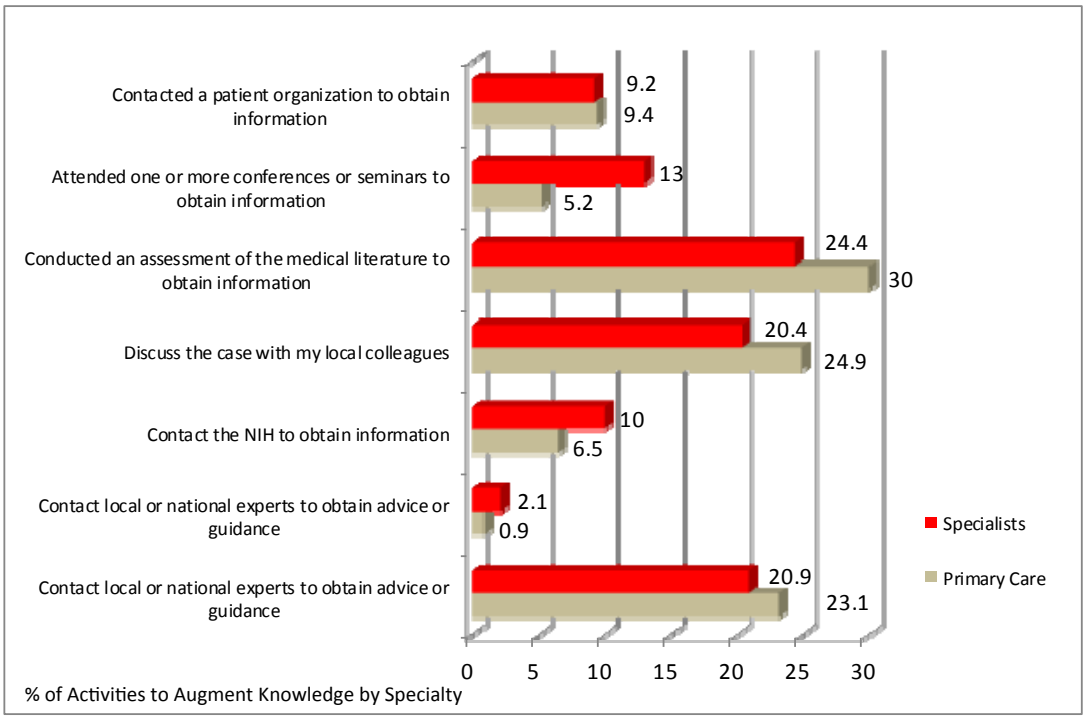

Figure 7. Activities undertaken to augment rare disease knowledge, by specialty.

The respondents overall rating of their training in rare diseases was impacted by specialty, with most (56.7%) of the primary care respondents rating their training as neutral, ineffective, or very ineffective, compared with 40% of specialists (**Figure 8**). Interestingly, 78.4% of primary care physicians and 80.9% of specialists stated that they had hands-on experience with a patient or patients with a rare disease during their training. The number of patients that respondents cared for during their training differed slightly between primary care and specialist respondents, with primary care physicians seeing an average of 43.1 patients with a rare disease during their training and specialists seeing an average of 68.8 patients.

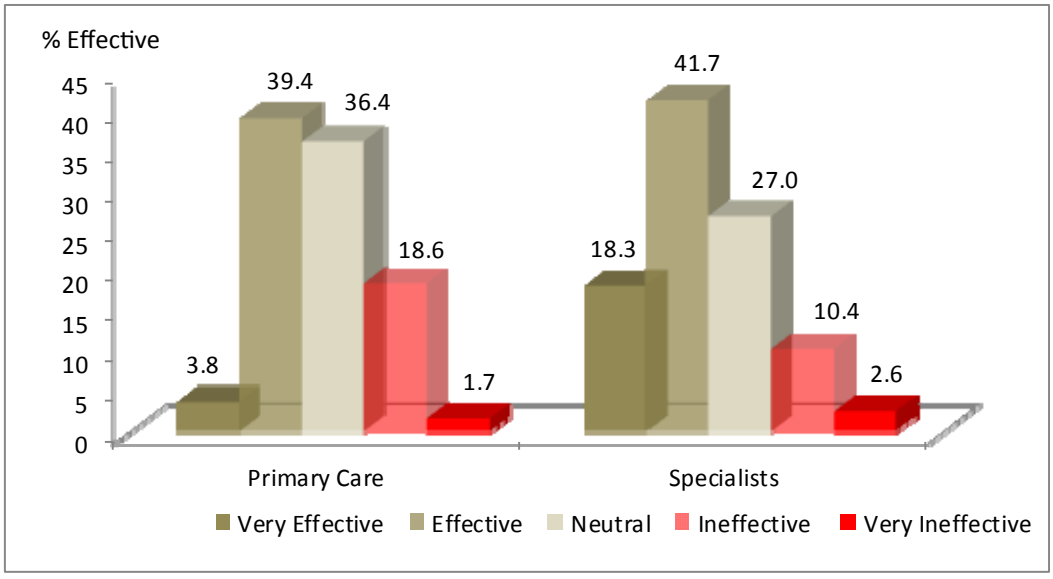

Figure 8. Perception of effectiveness of rare disease training, by specialty.

The survey also assessed the expectations of physicians regarding how involved they should be in the diagnosis of rare diseases. As shown in Figure 9, the percentage of respondents who agreed or strongly agreed with expectations of those in their specialty was consistent, with both primary care providers and specialists responding that physicians should be educated about the existence of rare diseases and be trained not only to identify symptoms indicative of a rare disease, but also to seek the help of others and refer patients if necessary to aid in diagnosis. Specialists were more likely to believe that they should be fully trained in the diagnosis of rare diseases and should take a leadership role in diagnosis.

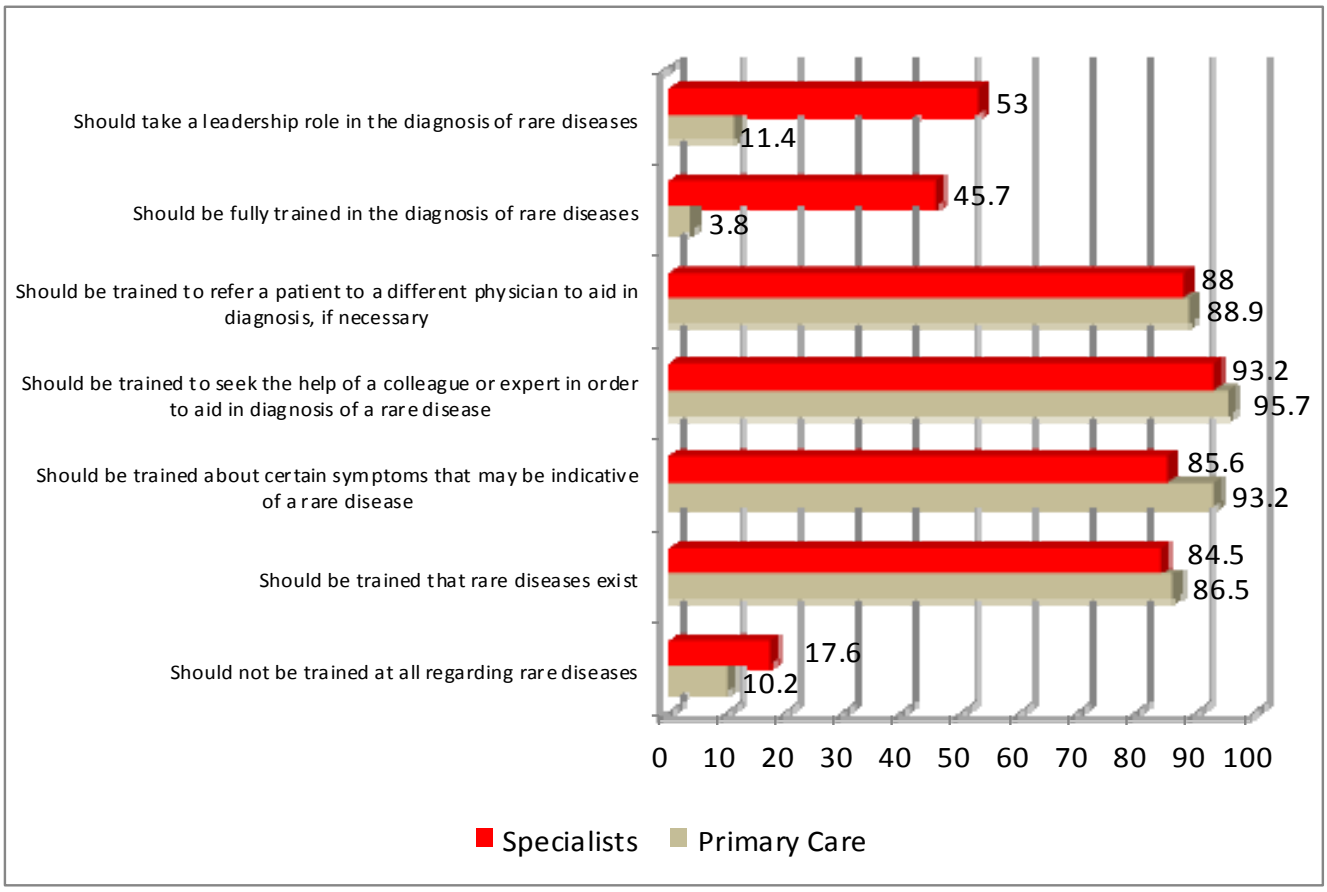

Figure 9. Percentage of HCPs who agreed or strongly agreed with statements regarding their role in rare disease diagnosis, by specialty.

Patients, Parents of Patients, and Spouses

Data obtained from the perspective of the patient showed a much more pessimistic picture. On average, the patients reported that it took between 0 and 20 years to obtain a diagnosis from the onset of symptoms (mean of 4.8 years). Patients were most likely to choose the statement "Because of a slow diagnosis, treatment was delayed and the impact on my condition has been negative" to characterize the impact of the speed of diagnosis on their disease. Notably, more than 30% of patients chose the statement "There is no treatment or intervention for my disease, the speed of diagnosis had no impact on my condition" (**Figure 10**)

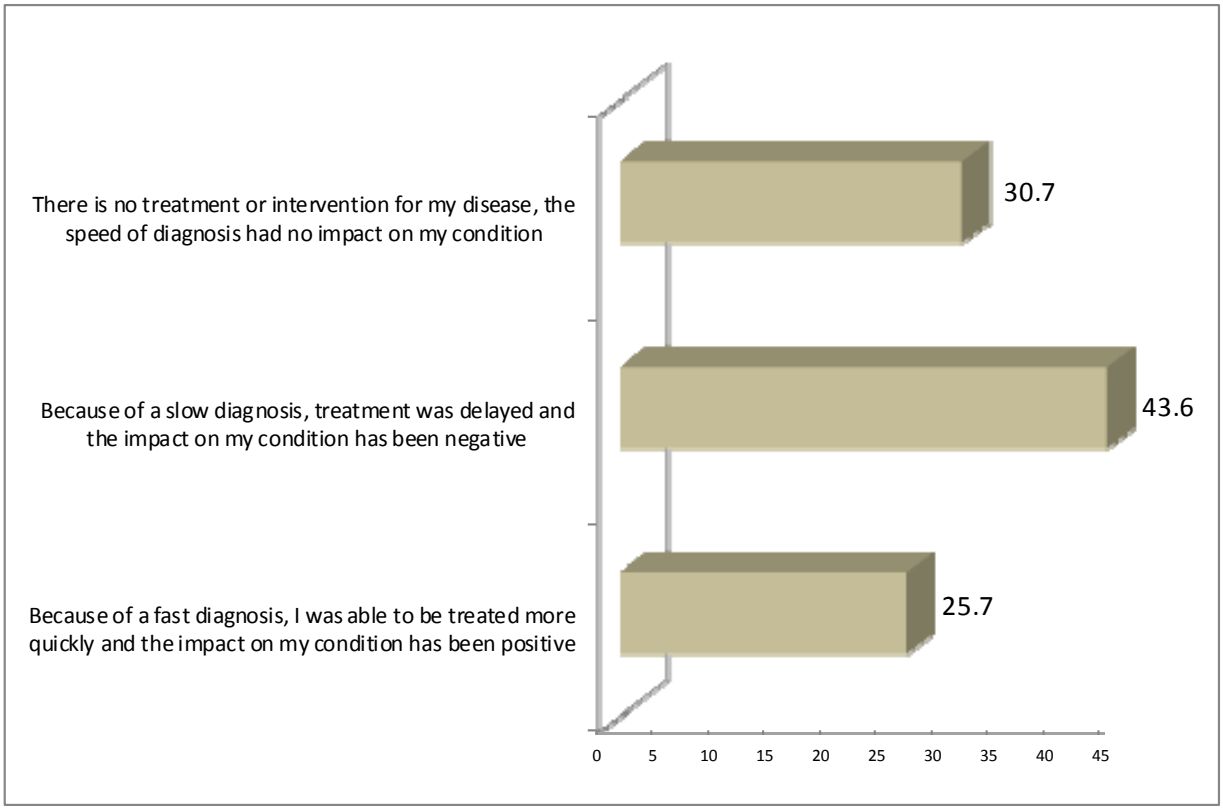

Figure 10. Patient perception of the impact of speed of diagnosis on their condition.

At the first onset of symptoms, patients most often saw a local primary care physician (73.3%), compared with a local specialist (17.2%), regional specialist (6.6%), or national specialist (2.9%). Patients reported seeing an average of 7.3 physicians before a diagnosis was made (range, 1–300). The physician who made the diagnosis was most often a local specialist (43.9% of cases), rather than a local primary care physician (11.2% of cases), a regional specialist (28.3% of cases), or a national specialist (16.6% of cases).

As shown in **Table 4,** the specialist who most often made the diagnosis was a neurologist or geneticist, but these data should be viewed with caution, as they are likely to be subject to bias based on the diseases represented by the mix of patients who responded to the survey.

Table 4. Specialties of HCPs Who Made the Rare Disease Diagnosis.

	Specialty	Percent	Specialty	Percent
Specialists (85.8%)	Allergy/Immunology	3.0		
	Biochemistry	0.1		
	Cardiology	0.7	Pediatric focus	0.8
	Dermatology	2.6	Pediatric focus	0.8
	Developmental pediatrics	0.4		
	Emergency medicine	0.5		
	Endocrinology	3.2	Pediatric focus	0.7
	Ear, nose, and throat	0.5		
	Epidemiology	0.1		
	Gastroenterology	0.6	Pediatric focus	0.2
	Genetics	11.9	Pediatric focus	7.9
	Hematology-Oncology	2.3	Pediatric focus	0.6
	Infectious diseases	0.4	Pediatric focus	0.1
	Internal medicine	2.9	Pediatric focus	0.7
	Metabolics	0.9		
	Neonatology	0.5		
Specialists (85.8%)	Nephrology	0.7	Pediatric focus	0.3
	Neurosurgery	1.1		
	Neurology	13.5	Pediatric focus	9.7
	Neuromuscular	0.5		
	Ob/Gyn	0.4		
	Ophthalmology	3.4	Pediatric focus	1.0
	Orthopedics	1.0	Pediatric focus	0.6
	Otolaryngology	0.2		
	Pain	0.2		
	Pathology	0.2		
	Pulmonology	1.5	Pediatric focus	0.5
	Psychology	0.1		
	Radiology	0.4		
	Rheumatology	3.6	Pediatric focus	2.4
	Sleep	0.2		
	Surgery	0.8		
	Urology	0.3		
	Other Special	1.0		
	Family practice	1.0		
	General practice	1.2		
	Nurse or physician asst	0.4		
	Pediatrics	2.2		
	Unknown	8.3		
	Doctor name	0.3		
	Self	0.8		

When patients were asked to rate their physicians' knowledge of rare diseases, they rated the knowledge of those who made the diagnosis much higher than those whom they had first seen at the onset of symptoms. Patients gave a "poor" or "fair" rating to 63.2% of physicians first seen at symptoms onset, and to 22.7% of physicians who made the diagnosis (**Figure 11**).

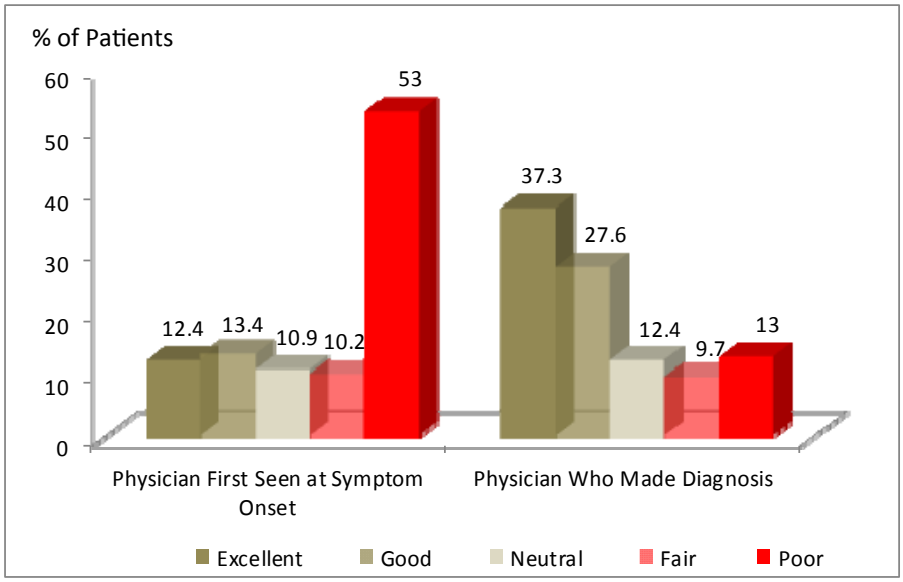

Figure 11. Patients' rating of their physicians' knowledge of rare diseases.

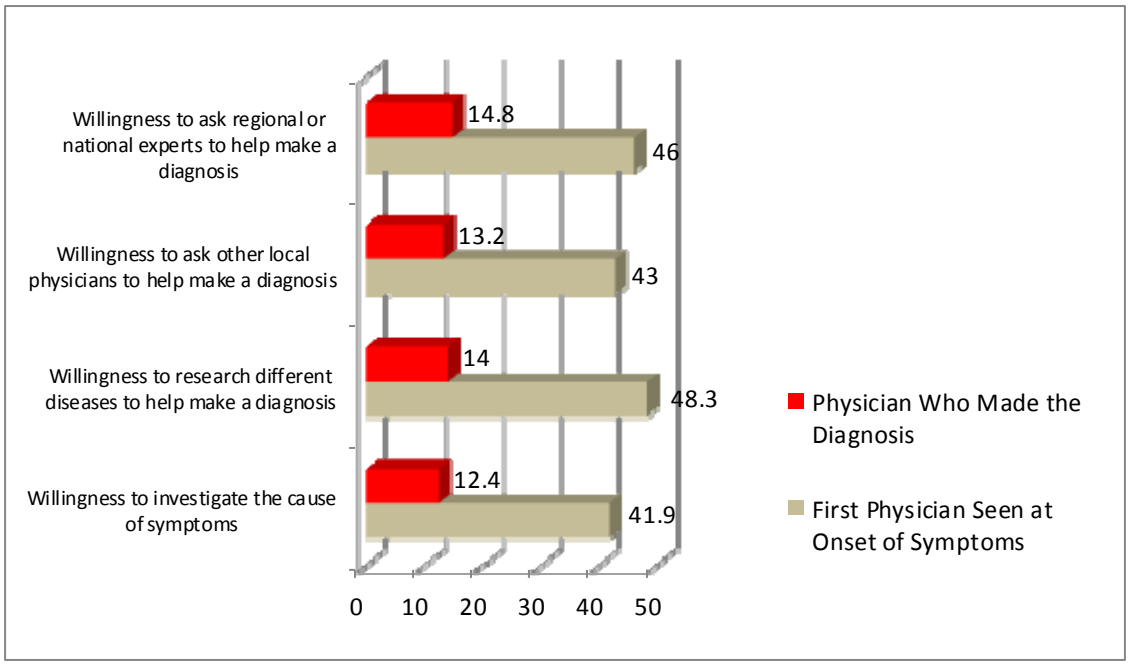

Figure 12. Patients' rating of their physician's willingness to aid in the diagnosis of a rare disease; by physician role**.**

Patients' satisfaction with physicians was assessed based on their willingness to perform certain activities that aided in diagnosis of the rare disease. As shown in **Figure 12**, nearly half of the patients were "very dissatisfied" or "dissatisfied" with the willingness of the first physician seen at onset of symptoms to become involved in a number of aspects of the rare disease diagnosis. Patients were much less likely to rate their satisfaction of the physician who made the diagnosis as "very dissatisfied" or "dissatisfied."

Likewise, patients were more likely to ascribe “no training in rare diseases” or “a small amount of training in rare diseases” to the physicians they had seen at the onset of symptoms (37.4%) compared with those who had made the diagnosis in their case (16.3%) (**Figure 13**). For physicians seen at the onset of symptoms, patients reported learning about the physician’s training from the physicians themselves 39.3% of the time and surmised it from their observation 51.7% of the time. For physicians who made the diagnosis, patients reported learning about the physician’s training from the physicians themselves 45.6% of the time and surmised it from their observation 38.8% of the time.

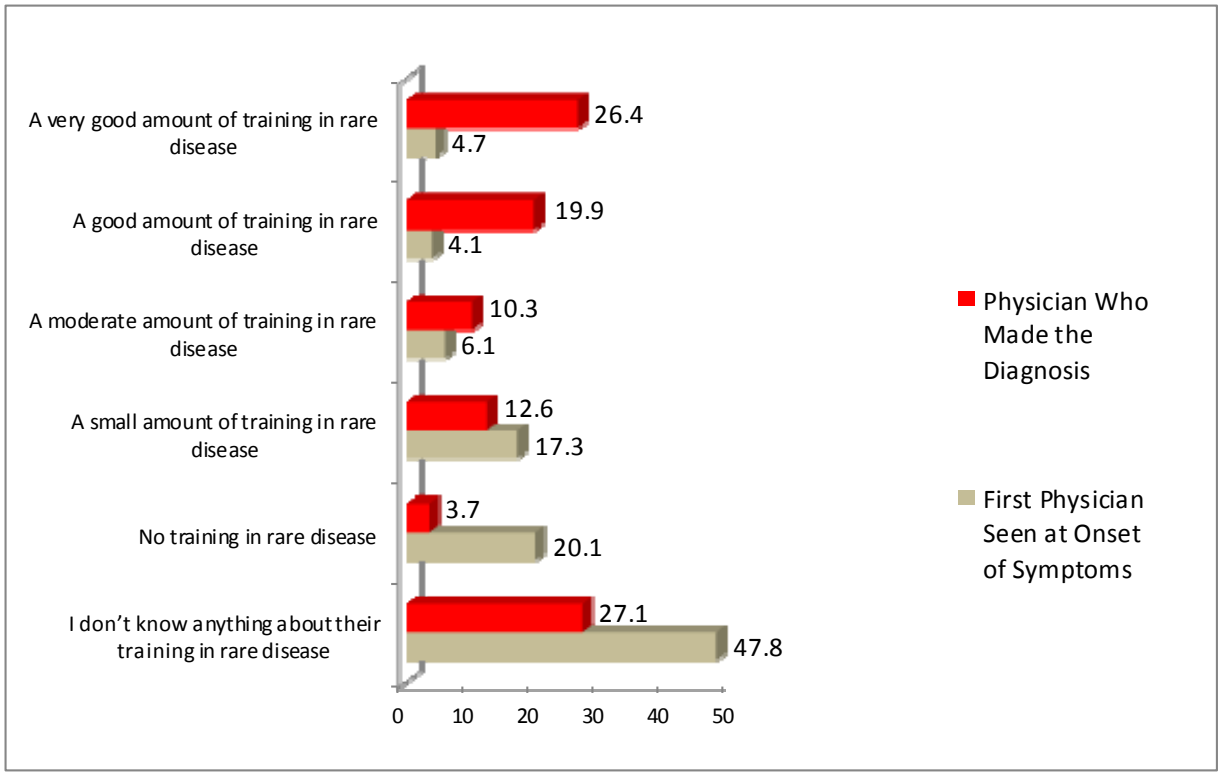

Figure 13. Patient knowledge or perception of physician training in rare diseases, by role of physician.

Furthermore, 62.3% of patients noted that they were “very satisfied” or “satisfied” with the training of the physician who made the diagnosis of their rare disease.

Like physicians, patients were realistic about the role of the primary care provider and the specialist in rare disease diagnosis, with 95% or greater noting that they “agree” or “strongly agree” that physicians should seek help and refer a patient quickly to obtain a diagnosis, with 97% or greater believing that specialists should be educated about the existence of rare diseases and be trained not only to identify symptoms indicative of a rare disease, but also to seek the help of others and refer patients if necessary to aid in diagnosis. Patients’ expectations were only slightly lower for primary care providers than for specialists (**Figure 14**).

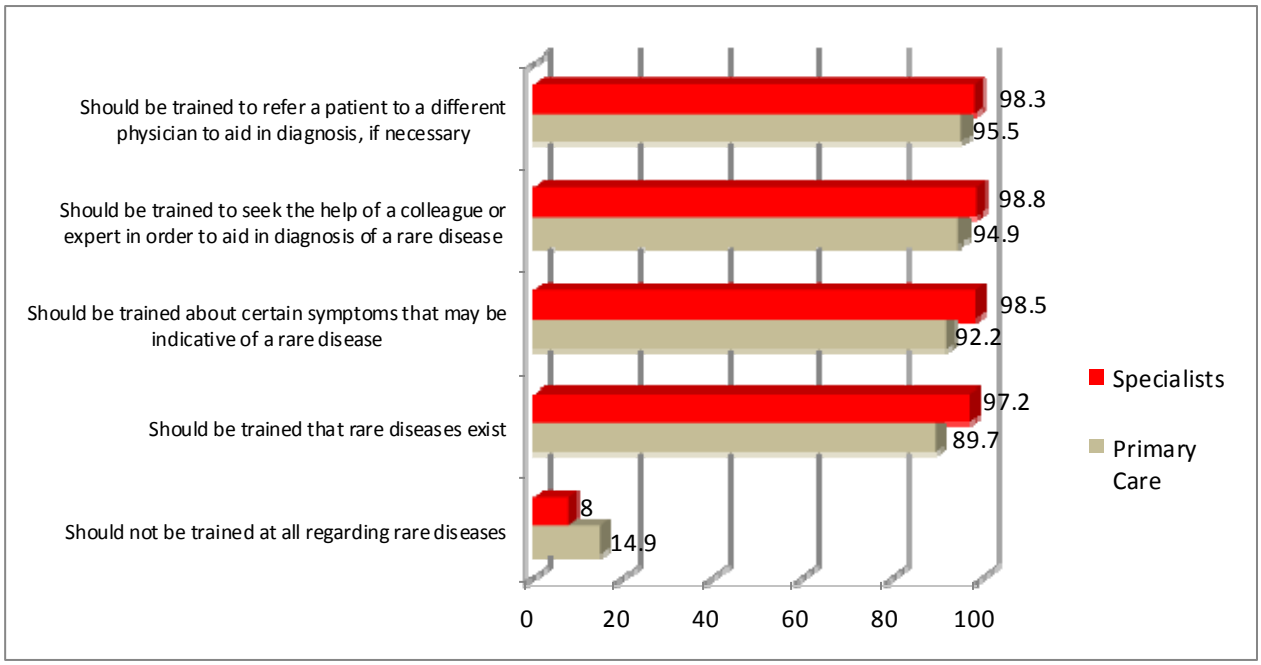

Figure 14. Percentage of patients who agreed or strongly agreed regarding the role of the physician in rare disease diagnosis, by specialty.

GOING FORWARD

While physicians and patients agree that there is a need for the consultation of experts and rapid referral to aid in the quick diagnosis of rare diseases, the data from this study reveal that what is occurring in clinical practice in the United States represents a less-than-ideal experience for patients with rare diseases.

Patients reported that they most often visit a local primary care physician at the onset of rare disease symptoms, and primary care physicians reported that they most often suspect something is wrong and refer patients. Although patients validated that they were referred to other physicians by primary care providers, they unfortunately saw an average of 7.3 physicians before a diagnosis was made. These data suggest that referrals are not targeted correctly, or that the referred physicians are not well versed in the diagnosis of rare diseases. This is not surprising, as many rare diseases are heterogeneous in nature, and the presenting symptoms in a patient may suggest referral to a certain type of physician who is not well versed in the diagnosis of that particular disease. Most physicians in this survey (70%) believed that it would be helpful to receive additional training in rare diseases, and patients rated the rare disease knowledge of the physician they saw at onset of symptoms as “poor” or “fair.”

Although there has been a good deal of dialogue about the need to refer patients, it appears that robust educational programs regarding targeting referrals or how to diagnose a rare disease in referred patients are also necessary.

We are currently experiencing an unprecedented interest in the development of rare disease therapies[14]; however, without the support of physician education, increased attention may only lead to additional wasted time and health care resources as patients go from physician to physician seeking a diagnosis.

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