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Providers' Perspectives on Treating Patients With Thalassemia

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Summary:

In recent years, California has experienced a steady rise in Asian immigration which has led to a corresponding increased prevalence of clinically significant thalassemia in this state. As part of the Public Health Research, Education and Surveillance for Hemoglobinopathies emoglobinopathies project, a survey was developed to collect information from California providers who care for thalassemia patients in an effort to better understand their practice patterns, barriers to providing care, and educational needs. When asked about educational needs, providers most frequently expressed a desire for care and management guidelines (65.3%), health educational materials for patients (47.2%), and information on complications and clinical outcomes (32.1%). Only one quarter of providers (24.0%) reported that all of their thalassemia patients have a coordinated care plan. The increase in California thalassemia cases highlights the importance of provider knowledge to effectively serve the patients in their communities. Provider education and dissemination of treatment standards can not only improve knowledge about the disease but also increase awareness about the importance of coordinating care among a multidisciplinary team of specialists. Improvement in these areas will help achieve the overarching goal of better outcomes and quality of life for patients with thalassemia.

Keywords

thalassemia; coordinated care; barriers; provider knowledge

Thalassemia is an inherited hematologic disorder caused by defects in the synthesis of the α or β subunit of hemoglobin.[1] Thalassemia is a global public health issue that is primarily found in Asian, Indian, and Middle Eastern regions and among those with ancestry from these areas.[2] In the United States, thalassemia is classified as a rare disorder as its clinically significant forms affect <200,000 people in the general population.[3] However, changing demographics, particularly Asian immigration, have resulted in thalassemia becoming a more significant public health concern in the United States.[4]

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One challenge that people with rare disorders often face is health care providers' lack of knowledge about their condition.[5] Although it would be impossible for providers to be knowledgeable about all rare diseases, it is important for them to be aware of those that are prevalent in the communities they serve. Over the past few decades, California has experienced a steady rise in Asian immigration. This has led to a corresponding increased prevalence of clinically significant thalassemia, particularly α-thalassemia, in this state.[6]

In 2012, the Centers for Disease Control and Prevention initiated the Public Health Research, Education and Surveillance for Hemoglobinopathies (PHRESH) project focused on using surveillance data to enhance health promotion and prevention of health complications.[7] As part of California's participation in PHRESH, a survey was developed to collect information from providers who care for thalassemia patients in the state in an effort to better understand their practice patterns, barriers to providing care, and educational needs. This paper presents the results of that survey to allow for an understanding of treating patients with thalassemia from the provider perspective, which is vital to tailoring programs and services designed to improve patient outcomes and quality of life.

MATERIALS AND METHODS

Technical input about the survey was provided by the PHRESH Project Thalassemia Advisory Committee, project partners at University of California San Francisco Benioff Children's Hospital Oakland, Children's Hospital Los Angeles, and staff at the Genetic Disease Screening Program of the California Department of Public Health. Providers were asked 10 questions in the survey. The survey collected information on providers' characteristics (eg, type of medical practice), experience with thalassemia patients (eg, number of current patients with thalassemia), educational needs about thalassemia, familiarity with thalassemia treatment and management standards, and barriers or challenges in thalassemia treatment (eg, challenges when coordinating care with other specialists). Providers were given the option to provide their contact information for follow-up information on thalassemia, and these names and emails were shared with thalassemia outreach staff at Benioff Children's Hospital Oakland to contact.

Providers were targeted for the mailing if (1) they were listed in the Medical Board of California Licensure database as having an "active" medical practice including the areas of pediatrics, family practice, obstetrics/gynecology, general practice, cardiology, and/or hematology; and (2) they had a mailing address in cities determined to have the highest count of confirmed thalassemia cases reported to the State Newborn Screening Program. A total of 30 cities were targeted for the survey. The top 10 cities represented 48% of known thalassemia cases. The number of selected cities (and providers) in the mailing was limited by project funds. Each provider was sent a cover letter and the survey, along with a preaddressed stamped return envelope and a Thalassemia Fact Sheet that was developed as an educational tool by PHRESH project staff and partners. This was a one-time mailing and no incentives were provided for survey completion.

Descriptive analyses were performed on the survey data. Responses were stratified by providers' current number of thalassemia patients and type of medical practice. All analyses were conducted using SAS, version 9.4 (SAS Institute Inc., Cary, NC).

RESULTS

Of the 7521 providers who were mailed the survey, a total of 644 completed surveys were returned for a response rate of 8.6%. Providers who reported to have never encountered a thalassemia patient over the course of their practice were removed from the analysis (N = 70; 10.9%). Therefore, the final sample for analysis included 574 providers.

Among the survey respondents, the most common medical practices were pediatrics (35.7%), family practice (21.3%), and obstetrics/gynecology (17.1%) (Table 1). The majority of providers (54.1%) reported seeing ≥ 6 patients with thalassemia over the course of their time in practice. Over half of providers (56.1%) had current patients with confirmed thalassemia.

When asked about educational needs, providers most frequently expressed a desire for care and management guidelines (65.3%), health educational materials for patients (47.2%), and information on complications and clinical outcomes (32.1%) (Table 2). Providers' preferred methods for receiving thalassemia information included mailed newsletters (44.3%), through the http://thalassemia.com/ Web site (38.7%), and e-mailed newsletters (36.2%).

Nearly half of providers (43.2%) reported that the care of their thalassemia patients is primarily managed by other specialists, in conjunction with the reporting provider. Approximately one quarter of providers (23.9%) were not familiar with thalassemia treatment and management standards. Half of the providers (50.5%) had not experienced any barriers in providing care for patients with thalassemia. Of those who had experienced barriers, needing guidance or support from hematologists (19.7%) and lack of familiarity with treatment and management standards (17.1%) were the most commonly reported barriers. The majority of providers (77.4%) had not encountered any challenges when coordinating care with other specialists for their thalassemia patients. Only one quarter of providers (24.0%) reported that all of their thalassemia patients have a coordinated care plan.

Stratified by Number of Current Thalassemia Patients

Our analysis revealed differences in question responses according to the current number of thalassemia patients in their care (Table 2). When asked in what areas they would like to be informed, providers with ≥ 4 current thalassemia patients more frequently indicated a need for health education materials for patients (58.9%), thalassemia-related conferences, symposiums, webinars, and workshops (16.5%), information regarding current clinical trials (14.6%), and epidemiology (12.7%). In comparison, providers with 1 to 3 current thalassemia patients most frequently noted the need for more information about guidelines for care and management (70.7%) and information on complications and clinical outcomes (36.0%). Providers with ≥ 4 current thalassemia patients more frequently indicated that they were very familiar with thalassemia treatment and management standards (28.5%) compared with providers with 0 (6.2%) or 1 to 3 current patients (9.1%).

Stratified by Medical Practice Type

Our analysis also revealed differences by providers' medical practice type (pediatrics, family practice, obstetrics/gynecology, other specialists). Family physicians more frequently reported (52.5%) that they were solely or mainly responsible for the care of their thalassemia patients in comparison to obstetricians/gynecologists (34.7%) and pediatricians (26.9%). Family physicians were also the least familiar with thalassemia treatment and management standards, with 27.0% reporting that they were not familiar with them. When asked about barriers while providing care for thalassemia patients, family physicians reported the most barriers, specifically need for guidance or support from hematologists (23.8%) and lack of familiarity with treatment and management standards (26.2%).

DISCUSSION

The goal of this study was to understand the treatment of thalassemia patients from the perspective of providers in California. Although our findings are based on a limited response rate, the data does show that the main obstacle to providing care for these patients is a lack of knowledge about thalassemia guidelines for care and management standards. This is understandable given the rare nature of the condition, but thalassemia is increasing in prevalence in some areas and can have severe health impacts if managed inappropriately. For example, iron overload is the primary complication of regular transfusions.[8] Routine monitoring for iron toxicity and the effects of excessive chelation is required to manage iron overload effectively.[9] Therefore, it is critical that health care providers in these areas are able to identify high-risk populations and where to find reliable, evidence-based guidelines on thalassemia care.[10-14]

In 1990, California began screening all newborns for β-thalassemia and related hemoglobinopathies, including sickle cell disease (SCD). The newborn screening program added α-thalassemia in 1999.[6] Newborn screening aids in early identification and treatment, however, this must be combined with follow-up and education to have a meaningful impact on patient mortality.[15] Yet many primary care providers do not feel adequately prepared to manage follow-up care for children with a positive newborn screen.[16] Roughly a quarter of providers surveyed in our study were not familiar with thalassemia treatment and management standards, even though they all cared for at least 1 thalassemia patient. Lack of familiarity with treatment and management standards was also the most common barrier reported by family physicians. This is concerning given that family physicians more frequently reported (52.5%) that they were solely or mainly responsible for the care of their thalassemia patients and this group had the highest number of providers who were unfamiliar with treatment guidelines (27.0%). On the basis of this, future educational efforts should focus on providing guidelines for care and other treatment-related information specifically to family physicians.

Rare diseases pose a unique challenge for both the provider and the patient. Budych et al[5] evaluated the patient-provider interaction in the context of rare diseases and found that a third of them were patient-directed. In this scenario, the provider lacks expertise about the disease and the patient becomes the expert. A recent survey of family physician attitudes toward the management of SCD, another rare blood disorder, found that only 20.4% of

respondents felt comfortable with the treatment of SCD.[17] A knowledgeable and involved provider can positively impact a patient's health outcomes, especially when it comes to rare diseases like thalassemia.[5]

The majority of providers in our study indicated that the care of their patients with thalassemia is managed in combination with providers from other specialties and disciplines. However, only a quarter of providers had a coordinated care plan for all of their current thalassemia patients. Survival rates are better for patients who receive care at thalassemia centers.[18] Optimal treatment for patients with clinically significant thalassemia requires a multidisciplinary approach with coordination between thalassemia centers, local providers, and patients.[13]

Although previously infrequent, pregnancies in women with thalassemia are increasingly common.[19] Although women with thalassemia are typically identified before pregnancy, providers may wish to consider routine antenatal screening for those with thalassemia trait (who carry the genetic trait for thalassemia but do not usually experience any health problems), particularly in high-risk ethnic groups.[20] In addition, patients with thalassemia may believe that they have decreased fertility.[21] This belief may contribute to lower contraceptive use possibly leading to an unplanned pregnancy. Gynecologists and obstetricians were the third most prevalent provider group in our survey, and it is important that they are aware of their role in the obstetric care of women with thalassemia or thalassemia trait.

This study was subject to limitations. Because thalassemia is a rare disorder, we targeted providers in the 30 cities in the state with the highest birth rates of thalassemia. This targeted approach may explain why the majority of providers that responded (89.1%) had cared for a thalassemia patient over the course of their practice. Because the response rate was low and may have been biased toward those providers who do see or have seen patients with thalassemia, the results may not be representative of all providers in the state. Our study also did not assess additional provider characteristics that are likely to influence familiarity with thalassemias such as ethnicity, age, and site of training. Future research can expand on our work to include these factors.

The study identified a group of providers that may benefit from future education and health promotion efforts. For example, Centers for Disease Control and Prevention is currently working on a project that will identify ways to decrease health problems from blood transfusions and to show that reducing these problems improved overall health for patients. One aim of the project is to improve health care providers' knowledge about health problems from blood transfusions.[22] The providers that responded to our survey can serve as the target population for educational materials about blood transfusions and related complications.

The increase in California thalassemia cases, likely due to immigration patterns, highlights the importance of provider knowledge to effectively serve the patients in their communities. Provider education and dissemination of treatment standards[10-14] can not only improve knowledge about the disease but also increase awareness about the importance of

coordinating care among a multidisciplinary team of specialists. Improvement in these areas will help achieve the overarching goal of better outcomes and quality of life for patients with thalassemia.

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TABLE 1.

Provider Specialty and Experience With Thalassemia Patients (N=574)

	n (%)
Provider specialty *	
Pediatrics	204 (35.7)
Family practice	122 (21.3)
Obstetrics/gynecology	98 (17.1)
Cardiology	37 (6.5)
General practice	36 (6.3)
Hematology	27 (4.7)
Other specialists	79 (13.8)
No response	2 (0.3)
No. patients with thalassemia encountered over the course of their practice	
1-5 patients	236 (41.1)
6-10 patients	95 (16.6)
> 10 patients	215 (37.5)
Unknown	23 (4.0)
No response	5 (0.9)
No. current thalassemia patients	
None	146 (25.4)
1-3 patients	164 (28.6)
≥ 4 patients	158 (27.5)
Unknown	93 (16.2)
No response	13 (2.3)

* Mark all that apply; the total percentage may add to > 100.

TABLE 2.

Provider Educational Needs, Management, and Barriers Regarding Thalassemia—Summary and Stratified by Current Number of Thalassemia Patients and Provider Specialty

		No. Current Thalassemia Patients, n (%)*				Provider Specialty, n (%)*†			
	Total (N = 574), n (%)	None (N = 146)	1-3 (N = 164)	≥4 (N = 158)	Unknown (N = 93)	Pediatrics (N = 204)	Family Practice (N = 122)	Obstetrics/ Gynecology (N = 98)	Other Specialists‡ (N = 171)
Areas you would like to be more informed about with respect to thalassemia§									
Guidelines for care and management	375 (65.3)	81 (55.5)	116 (70.7)	103 (65.2)	68 (73.1)	144 (70.6)	86 (70.5)	64 (65.3)	93 (54.4)
Health education materials for patients	271 (47.2)	46 (31.5)	80 (48.8)	93 (58.9)	44 (47.3)	127 (62.3)	48 (39.3)	45 (45.9)	59 (34.5)
Complications and clinical outcomes	184 (32.1)	51 (34.9)	59 (36.0)	38 (24.1)	31 (33.3)	66 (32.4)	37 (30.3)	27 (27.6)	64 (37.4)
Thalassemia trait	170 (29.6)	35 (24.0)	53 (32.3)	53 (33.5)	24 (25.8)	83 (40.7)	37 (30.3)	26 (26.5)	31 (18.1)
Continuing educational opportunities	107 (18.6)	20 (13.7)	37 (22.6)	33 (20.9)	16 (17.2)	38 (18.6)	22 (18.0)	18 (18.4)	33 (19.3)
General genetics	95 (16.6)	23 (15.8)	26 (15.9)	29 (18.4)	15 (16.1)	46 (22.5)	12 (9.8)	19 (19.4)	23 (13.5)
Thalassemia-related conferences, symposiums, webinars, and workshops	57 (9.9)	8 (5.5)	16 (9.8)	26 (16.5)	7 (7.5)	25 (12.3)	10 (8.2)	3 (3.1)	24 (14.0)
Clinical trials	44 (7.7)	7 (4.8)	7 (4.3)	23 (14.6)	6 (6.5)	15 (7.4)	4 (3.3)	3 (3.1)	26 (15.2)
Epidemiology	41 (7.1)	8 (5.5)	7 (4.3)	20 (12.7)	6 (6.5)	16 (7.8)	11 (9.0)	4 (4.1)	12 (7.0)
Other specialists	31 (5.4)	10 (6.8)	3 (1.8)	9 (5.7)	8 (8.6)	8 (3.9)	7 (5.7)	9 (9.2)	8 (4.7)
No response	80 (13.9)	16 (11.0)	21 (12.8)	19 (12.0)	11 (11.8)	17 (8.3)	20 (16.4)	8 (8.2)	36 (21.1)
Preferred method for receiving the above information§									
Mailed newsletters	254 (44.3)	58 (39.7)	82 (50.0)	69 (43.7)	41 (44.1)	93 (45.6)	51 (41.8)	53 (54.1)	65 (38.0)
Through the http://thalassemia.com/Website	222 (38.7)	56 (38.4)	63 (38.4)	62 (39.2)	38 (40.9)	78 (38.2)	46 (37.7)	36 (36.7)	73 (42.7)
E-mailed newsletters	208 (36.2)	46 (31.5)	57 (34.8)	68 (43.0)	32 (34.4)	91 (44.6)	45 (36.9)	26 (26.5)	54 (31.6)
Webinars	54 (9.4)	11 (7.5)	16 (9.8)	17 (10.8)	8 (8.6)	18 (8.8)	14 (11.5)	7 (7.1)	17 (9.9)
One on 1 consultation/conversation with an expert	37 (6.4)	9 (6.2)	10 (6.1)	14 (8.9)	4 (4.3)	17 (8.3)	5 (4.1)	5 (5.1)	12 (7.0)
Electronic listserv to discuss individual cases	9 (1.6)	1 (0.7)	1 (0.6)	5 (3.2)	2 (2.2)	3 (1.5)	2 (1.6)	1 (1.0)	3 (1.8)
Other specialists	20 (3.5)	6 (4.1)	6 (3.7)	5 (3.2)	3 (3.2)	11 (5.4)	3 (2.5)	3 (3.1)	3 (1.8)
No response	45 (7.8)	15 (10.3)	10 (6.1)	9 (5.7)	7 (7.5)	7 (3.4)	8 (6.6)	6 (6.1)	24 (14.0)
Management of care for your patients' thalassemia									
Solely by you	55 (9.6)	7 (4.8)	20 (12.2)	22 (13.9)	5 (5.4)	17 (8.3)	14 (11.5)	2 (2.0)	23 (13.5)
Mainly by you and with other providers from different disciplines/specialties	141 (24.6)	19 (13.0)	41 (25.0)	63 (39.9)	18 (19.4)	38 (18.6)	50 (41.0)	32 (32.7)	28 (16.4)

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		None (N = 146)	1-3 (N = 164)	≥4 (N = 158)	Unknown (N = 93)	Pediatrics (N = 204)	Family Practice (N = 122)	Obstetrics/ Gynecology (N = 98)	Other Specialists‡ (N = 171)
Mainly by other specialists (eg, hematologist) but you are involved	248 (43.2)	71 (48.6)	83 (50.6)	48 (30.4)	41 (44.1)	122 (59.8)	38 (31.1)	41 (41.8)	57 (33.3)
Solely by other providers/specialists	78 (13.6)	29 (20.0)	16 (9.8)	8 (5.1)	22 (23.7)	13 (6.4)	11 (9.0)	16 (16.3)	40 (23.4)
Other specialists	28 (4.9)	12 (8.2)	3 (1.8)	9 (5.7)	3 (3.2)	3 (1.5)	5 (4.1)	4 (4.1)	17 (9.9)
No response	24 (4.2)	8 (5.5)	1 (0.6)	8 (5.1)	4 (4.3)	11 (5.4)	4 (3.3)	3 (3.1)	6 (3.5)
Familiarity with thalassemia treatment and management standards									
Very familiar	80 (13.9)	9 (6.2)	15 (9.1)	45 (28.5)	10 (10.8)	30 (14.7)	8 (6.6)	12 (9.8)	36 (21.1)
Somewhat familiar	347 (60.5)	85 (58.2)	112 (68.3)	96 (60.8)	48 (51.6)	132 (64.7)	79 (64.8)	64 (65.3)	81 (47.4)
Not familiar	137 (23.9)	48 (32.9)	37 (22.6)	13 (8.2)	34 (36.6)	38 (18.6)	33 (27.0)	21 (21.4)	50 (29.2)
No response	10 (1.7)	4 (2.7)	0 (0)	4 (2.5)	1 (1.1)	4 (2.0)	2 (1.6)	1 (1.0)	4 (2.3)
Barriers while providing care for patients with thalassemia§									
No barriers	290 (50.5)	73 (50.0)	89 (54.3)	73 (46.2)	49 (52.7)	112 (54.9)	53 (43.4)	53 (54.1)	85 (49.7)
Need guidance or support from hematologists	113 (19.7)	19 (13.0)	39 (23.8)	31 (19.6)	22 (23.7)	48 (23.5)	29 (23.8)	19 (19.4)	20 (11.7)
Lack of familiarity with treatment and management standards	98 (17.1)	19 (13.0)	28 (17.1)	29 (18.4)	20 (21.5)	25 (12.3)	32 (26.2)	20 (20.4)	23 (13.5)
Patients are not adherent to treatment regimens	54 (9.4)	6 (4.1)	13 (7.9)	27 (17.1)	7 (7.5)	20 (9.8)	10 (8.2)	7 (7.1)	21 (12.2)
Need more staff time to coordinate the care	51 (8.9)	13 (8.9)	11 (6.7)	21 (13.3)	5 (5.4)	17 (8.3)	9 (7.4)	4 (4.1)	22 (12.9)
Low or lack of reimbursement for the type of services provided	43 (7.5)	11 (7.5)	6 (3.7)	19 (12.0)	7 (7.5)	12 (5.9)	8 (6.6)	7 (7.1)	19 (11.1)
Other specialists	53 (9.2)	18 (12.3)	11 (6.7)	12 (7.6)	10 (10.8)	16 (7.8)	14 (11.5)	5 (5.1)	19 (11.1)
No response	31 (5.4)	14 (9.6)	5 (3.0)	2 (1.3)	7 (7.5)	10 (4.9)	2 (1.6)	7 (7.1)	12 (7.0)
Challenges when coordinating care with other specialists for your patients with thalassemia									
Yes	55 (9.6)	11 (7.5)	13 (7.9)	24 (15.2)	7 (7.5)	15 (7.4)	12 (9.8)	9 (9.2)	23 (13.5)
No	444 (77.4)	107 (73.3)	136 (82.9)	123 (77.8)	69 (74.2)	174 (85.3)	91 (74.6)	77 (78.6)	119 (69.6)
Unknown	52 (9.1)	18 (12.3)	10 (6.1)	9 (5.7)	13 (14.0)	12 (5.9)	17 (13.9)	7 (7.1)	16 (9.4)
No response	23 (4.0)	10 (6.8)	5 (3.0)	2 (1.3)	4 (4.3)	3 (1.5)	2 (1.6)	5 (5.1)	13 (7.6)
Current thalassemia patients with a coordinated care plan to manage their condition									
All of them	138 (24.0)	11 (7.5)	72 (43.9)	46 (29.1)	8 (8.6)	61 (29.9)	25 (20.5)	24 (24.5)	31 (18.1)
Some of them	113 (19.7)	5 (3.4)	26 (15.9)	67 (42.4)	15 (16.1)	29 (14.2)	26 (21.3)	19 (19.4)	42 (24.6)
None of them	51 (8.9)	1 (0.7)	29 (17.7)	16 (10.1)	4 (4.3)	17 (8.3)	19 (15.6)	4 (4.1)	12 (7.0)
I currently don’t have any patients with thalassemia	130 (22.6)	97 (66.4)	8 (4.9)	5 (3.2)	17 (18.3)	48 (23.5)	27 (22.1)	24 (24.5)	39 (22.8)

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	Total (N = 574), n (%)	No. Current Thalassemia Patients, n (%)*				Provider Specialty, n (%)*†			
		None (N = 146)	1-3 (N = 164)	≥4 (N = 158)	Unknown (N = 93)	Pediatrics (N = 204)	Family Practice (N = 122)	Obstetrics/ Gynecology (N = 98)	Other Specialists‡ (N = 171)
Unknown	109 (19.0)	14 (9.6)	26 (15.9)	21 (13.3)	44 (47.3)	41 (20.1)	21 (17.2)	19 (19.4)	34 (19.9)
No response	33 (5.7)	18 (12.3)	3 (1.8)	3 (1.9)	5 (5.4)	8 (3.9)	4 (3.3)	8 (8.2)	13 (7.6)

*Providers who did not respond to this question were not included in the denominator.

†Providers could choose >1 specialty.

‡Other category includes general practice, cardiology, hematology, and other specialists.

§Mark all that apply; the total percentage may add to > 100.