Original Article

Cystic fibrosis knowledge and practice among primary care physicians in southwest region, Saudi Arabia

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Abstract

Introduction: Cystic fibrosis (CF) is a multisystem autosomal recessive disease that affects 1 in 4,000 newborns in the United States and has high mortality and morbidity. In the Middle East, there is no exact estimation of CF prevalence and the survival rate is almost 50% of the reported survival in the developed countries. In this study, I aimed to determine the CF knowledge and practice (CF-KP) among primary care physicians (PCPs) and to propose effective educational programs to recognize children who suffer from CF early on and refer them to appropriate tertiary centers. **Materials and Methods:** This was a cross-sectional study among PCPs in the Aseer region. The principal investigator designed and formulated the used CF-KP questionnaire in this study. It was developed in the English language and distributed through Google and printed forms. Each question included right and wrong answers with the ability to choose more than one option. There were three categories for each question either answer completely, incompletely, or wrong answer. **Results:** Fifty-one PCPs were recruited and successfully completed the questionnaire. Around two-thirds of the responders were less than 40 years old while few were older than 50 years. The majority of the responding doctors were male 82.4% (42 out of 51) and have been practicing clinical medicine more than 5 years after graduation. The overall knowledge score percent was 56.7% with a mean of 20.4, maximum 31, and minimum 4, while the overall practice score percent was 68% with a mean of 3.4 and maximum and minimum scores were 5 and 1, respectively. **Discussion:** This study is the first study that assessed the CF-KP among PCPs in the Aseer region. The total score percent of knowledge and practice among the studied group were 56% and 68%, respectively. Around 20% of the responding physicians knew when to refer suspected cases of CF to a tertiary center for further diagnostic and therapeutic interventions. Most of the responders in this study did not know the long-term complications of CF and they did not think that it is a progressive disease and eventually cause death if untreated. **Conclusion:** This study highlighted the need for extensive educational programs for the PCPs in order to improve early recognition of CF and start the appropriate management. In the era of CF modulators and correctors, CF providers should maximize the other therapies to improve the outcomes and prevent long-term morbidities and mortalities.

Keywords: Cystic fibrosis, knowledge and practice, primary care physicians

Introduction

Cystic fibrosis (CF) is a multisystem autosomal recessive disease that affects 1 in 4,000 newborns in the United States and has high mortality and morbidity.[1] The basic CF genetic defect is gene mutations in the CF transmembrane conductance regulator (CFTR) that lead to CFTR channel dysfunction and subsequently impair chloride transportation across the epithelial membranes of the airways, gastrointestinal tract, and reproductive system.[2] Pulmonary and gastrointestinal manifestations are the most common presenting symptoms in children and they have a huge impact on the long-term survival of CF.[3-6] Early diagnosis of CF, especially through newborn screening programs, has impacted the quality of life and slow the decline in lung function.[7,8] In the countries that have well-established newborn screening programs and CF care

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centers, the estimated survivals are more than 40 years.[1,9-11] However, in the middle east, there is no exact estimation of CF prevalence and the survival rate is almost 50% of the reported survival in the developed countries.[8,10-13] One of the reasons for the improvement of survival is the establishment of newborn screening programs and early recognition and interventions for pulmonary manifestations.[14,15] In Saudi Arabia (SA), the median age of CF diagnosis is around 3 years due to a lack of newborn screening and probable lack of awareness about the disease at the level of the PCPs.[6,12] In this study, i aimed to determine the knowledge and practice of PCPs about CF and to propose effective educational programs to recognize children who suffer from CF early on and refer them to appropriate tertiary centers.

Materials and Methods

Study design and setting

This was a cross-sectional study among primary care physicians (PCPs) in the Aseer region. The PCPs were defined as the doctors who worked at the primary care centers and classified from the Saudi council for health specialty (SCFHS) to practice medicine in the kingdom. The targeted doctors were residents, specialists, and family medicine consultants. The study included government-based primary care centers.

Aseer region is one of the 13 regions of the kingdom of SA with more than 2 million total populations and it is located at around 7000 feet above the sea level. The region has two main geographical distributions which include the high-altitude level and sea-level living populations. The region has more than 280 primary care centers and more than 300 PCPs are working in these centers. The primary care settings in SA are considered the first line of care that receive most of the children for well-baby checks and routine vaccinations. The research was approved by the Research and Ethics Committee of Abha Maternity and Children Hospital, Abha, Saudi Arabia.

Study instrument

The principal investigator designed and formulated the used CF-KP questionnaire in this study (see Appendix-1). It was developed in the English language and distributed through Google and printed forms. The form contained two main domains, that is, knowledge and practice about CF. There were 10 knowledge and 3 practice questions that tested different aspects of CF background information. The knowledge questions covered definition, mode of inheritance, typical CF symptoms, diagnostic tools, common clinical presentations, treatment modalities, complications, similarities and differences between CF and asthma, and national and international CF mean survival. In addition, the practice questions included when to refer suspected cases of CF to specialized centers, what to do in case of acute CF pulmonary exacerbations, and standard follow-up care for proved cases of CF.

To establish the questionnaire validity and clarity of the questions, it was tested among 20 PCPs and their feedback about the questions was collected. Those 20 PCPs were excluded from the final study sample. The questionnaire was also sent for three national experts to rate the importance of the questions and their relevance to the real clinical practice. Questions were included if they were rated important or extremely important, using three points scale (not important, important, extremely important).

Questionnaire scoring

Each question included right and wrong answers with the ability to choose more than one option. There were three categories for each question either answer completely, incompletely, and wrong answer. Complete means the responder chose all right answers, incomplete means choosing some right and some wrong answers, and wrong means that the responder chose all wrong answers. The total knowledge score was calculated for all the right answers in all questions and each responder's total score was determined as per his/her right answers.

Demographic variables and sampling

The first section of the questionnaire contained important demographics that include age, gender, years of experience after graduation and in a primary care setting, nationality, job nature (resident, specialist, family medicine consultant), and whether the responder has ever attended the yearly educational pediatric club meeting. The PCPs were recruited via convenience sampling.

Statistical analyses

Data were represented as counts and percentages. The total knowledge and practice scores were calculated as median and percentage out of the total scores. The total score of knowledge was calculated through the summation of all correct answers (37 points), while the practice score was out of 5 points.

Results

Fifty-one PCPs were recruited and successfully completed the questionnaire. Around two-thirds of the responders were less than 40 years old while few were older than 50 years. The majority of the responding doctors were male 42/51 (82.4%) and have been practicing clinical medicine more than 5 years after graduation. Only 6/51 (11.8) had attended the yearly educational regional pediatric club meeting. Most of the responders were working as general practitioners 29/51 (56.8%) while others were either specialists or family medicine consultants 22/51 (43.2%) [Table 1].

10% (5/51) of the responding physicians defined CF correctly while the remaining 90% (46 out of 51) either defined it incompletely or wrong. 34 (66.7%) knew the mode of inheritance of CF which represents two-thirds. All responders answered the question of typical symptoms of CF incompletely. Less than 10%, 7.8% (4 out of 51), answered correctly and completely the therapeutic modalities of CF. Regarding the complications of CF, 41.2% (21 out of 51) chose all possible acute and chronic

complications. Considering the differences between asthma and CF, 17.6% (9 out of 51) knew the differences between the two respiratory illnesses. The complete answers about the questions of mean CF survival nationally and internationally were as the following 7.8% (4 out of 51) and 58.8% (30 out of 51), respectively. The overall knowledge score was 56.7% (mean of 20.4, maximum 31, and minimum 4) [Table 2].

Table 1: Demographic characteristics of the responding physicians (*n*=51)

Demographic characteristics	Frequency	Percent
Age in years		
Less than 40 years old	33	67.7
40-50 years	9	17.6
51-60 years	8	15.7
More than 60 years	1	2.0
Gender		
Female	9	17.6
Male	42	82.4
Years of experience since graduation		
Less than 5 years	3	5.9
5-10 years	25	49.0
More than 10 years	23	45.1
Years of experience in the primary health care field		
5-10 years	27	52.9
Less than 5 years	6	11.8
Over 10 years	18	35.3
Nationality		
Arabic other than Saudi	31	60.8
Non-Arabic	4	7.8
Saudi Arabia	16	31.4
Job nature		
Consultant	11	21.5
General practitioner	29	56.8
Specialist	11	21.5
Have you ever attended the Aseer Pediatric Club meeting?		
No	45	88.2
Yes	6	11.8
Total	51	100.0

The overall practice score percent was 68% with a mean of 3.4 and maximum and minimum scores were 5 and 1, respectively. Regarding the practice of PCPs about when to refer suspected CF patients, 19.6% (10 out of 51) responded correctly and the remaining either answered incorrectly or incompletely. More than 50% (28 out of 51) of the responders answered correctly about the management of acute pulmonary exacerbations for the patients who are known with CF. On the other hand, less than 50% (23 out of 51) knew the standard of care to follow up with children who are known to have the diagnosis of CF [Table 3].

Discussion

This study is the first study that assessed the knowledge and practice of PCPs about CF in the southwest region of SA. The rationale for conducting this study due to the late diagnosis of CF in SA; the median age of diagnosis of CF in SA is around 3 years.[6,12] The total score percent of knowledge and practice among the studied group was 56% and 68%, respectively. The lack of knowledge and subsequently late discovery, about this high burden disease, do lead to high mortality and morbidities.[12] Since the PCPs are the first care providers in the health care systems, health organizations should target their educational activities to these doctors in order to improve their knowledge about this disease.

In developed countries, the most important determinants of morbidity and mortality among CF patients are malnutrition and early respiratory system bacterial colonization.[8,16,17] Local reports have estimated the median survival of CF patients in SA between 10 and 20 years which is far away from the international CF survival, especially countries that have a high prevalence of CF.[10,12] Based on the last reports from the United States and Canada CF registries, the estimated median survivals of CF patients are the late 30s and late 40s, respectively.[18] In addition, the median survival between CF patients in the United Kingdom differentiates between the type of mutations and their reported estimated ages were between the 40s and late 50s.[10,19] Early diagnosis of CF in

Table 2: Responses about cystic fibrosis knowledge among primary care physicians

No.	Knowledge questions	Responding completely No (%)	Responding incompletely No (%)	Responding wrongly No (%)
1	Definition of cystic fibrosis	5 (10.0%)	34 (66.7%)	12 (23.5%)
2	Mode of inheritance of cystic fibrosis	34 (66.7%)	0 (0)	17 (33.3%)
3	Typical symptoms of cystic fibrosis in children	0 (0%)	51 (100%)	0 (0%)
4	Diagnostic tools of cystic fibrosis	35 (68.6%)	14 (27.5%)	2 (4.0%)
5	Possible presentations of cystic fibrosis	25 (40.0%)	15 (29.4%)	11 (21.6%)
6	Therapeutic modalities of cystic fibrosis	4 (7.8%)	8 (15.7%)	39 (76.5%)
7	Complications of cystic fibrosis	21 (41.2%)	30 (58.8%)	0 (0%)
8	Differences between asthma and cystic fibrosis	9 (17.6%)	9 (17.6%)	33 (64.7%)
9	Mean survival of patient with cystic fibrosis in Saudi Arabia	4 (7.8%)	31 (60.8%)	16 (31.4%)
10	Mean survival of patient with cystic fibrosis worldwide	30 (58.8%)	17 (33.3%)	4 (7.8%)
Overall knowledge score (percent)			20.4 (56.7%) max and min (31-4)	

Table 3: Responses about cystic fibrosis practice among primary care physicians

No.	Item	Responding completely No (%)	Responding incompletely No (%)	Responding wrongly No (%)
1	Referring suspected cases of cystic fibrosis to specialized center	10 (19.6%)	29 (56.8%)	12 (25.4%)
2	Treating of cystic fibrosis acute pulmonary exacerbation	28 (54.9%)	0 (0%)	23 (45.1%)
3	Regular follow-up of patients with cystic fibrosis	23 (45.1%)	0 (0%)	28 (54.9%)
Overall practice score (percent)			3.4 (68%) max and min (5-1)	

the first months of life will help to start the effective treatments that would improve the nutrition and delay the acquisition of pulmonary pathogens that contribute heavily to the rapid decline of lung function during late childhood and adolescence.[13,15,20]

Around 20% of the responding physicians knew when to refer suspected cases of CF to a tertiary center for further diagnostic and therapeutic interventions. Wide educational activities are highly recommended at the level of the primary care settings to help early recognition of children with CF. Most of the responders in this study did not know the long-term complications of CF and they did not think that it is a progressive disease and eventually cause death if untreated. On the other hand, around 50% of the targeted doctors knew that established patients with CF need regular follow-up and urgent evaluation at the hospital with any signs of pulmonary exacerbations. The chosen answers were based on the last US CF Foundation Pulmonary Guidelines which recommended monthly visits in the first year and every 3 months thereafter.[4,15,20] The CF Foundation also recommended easy access for health care for any CF with any early signs of pulmonary exacerbation or other comorbid illnesses.[10]

In the countries that have a high prevalence of CF, specifically North American and the United Kingdom, the establishment of health care centers and care guidelines have improved the CF patients' care drastically.[11,21] This study highlighted the need for clear and nationwide standardized guidelines for establishing the diagnosis and starting the appropriate management. However, before establishing such CF centers, we need a real and accurate estimate of the CF among Saudi children to target the highly prevalent areas. Such programs are important to catch those children early in the course of the disease to improve morbidity and mortality especially with the new CF treatments.

The new CF treatments are based on the specific genotype which mandates early diagnosis and early introduction of these therapies in order to improve survival and avoid long-term modalities.[22]

Conclusion

This study highlighted the need for extensive educational programs for the PCPs in order to improve early recognition of CF and start the appropriate management. In the era of CF modulators and correctors, CF providers should maximize other therapies to improve the outcomes and prevent long-term morbidities and mortalities.

Disclosure

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Conflicts of interest

There are no conflicts of interest

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Appendix-1

A- Demographic characteristics of the responding physicians

1- Age in years
   a. Less than 40 years old
   b. 40–50 years
   c. 51–60 years
   d. Over 60 years

2- Gender
   a. Female
   b. Male

3- Nature of your setting
   a. Private
   b. Government

4- Years of experience since graduation
   a. Less than 5 years
   b. 5–10 years
   c. More than 10 years

5- Years of experience in the primary health care field
   a. Less than 5 years
   b. 5–10 years
   c. Over 10 years

6- Nationality
   a. Arabic other than Saudi
   b. Non-Arabic
   c. Saudi Arabia

7- Job nature
   a. General practitioner
   b. Specialist
   c. Consultant

8- Have you ever attended the Aseer Pediatric Club meeting?
   a. Yes
   b. No

B- Knowledge Questions

1- Choose the right definition of cystic fibrosis? (Can check more than one answer)
   a. Cystic fibrosis is a chronic multisystem disease causing mainly lung and gastrointestinal symptoms.
   b. Cystic fibrosis causes acute exacerbation and affects mainly lungs.
   c. Cystic fibrosis causes chronic cough and a skin rash that responds well to inhaled steroids.
   d. Cystic fibrosis causes chronic diarrhea and seizures.
   e. Cystic fibrosis causes failure to thrive due to chronic heart failure and chronic cough.
   f. Cystic fibrosis causes progressive lung disease that eventually leads to chronic respiratory failure and death in the mid-twenties.
   g. Cystic fibrosis causes recurrent wheezing and cough without long term chronic respiratory complications.
   h. Don't know

2- What is the mode of inheritance of cystic fibrosis? (Can check more than one answer)
Check all that apply.

   a. Autosomal dominant
   b. Autosomal recessive
   c. X-linked dominant
   d. X-linked recessive
   e. Multifactorial
   f. Sporadic
   g. Don't know

3- Which of the following are considered symptoms of cystic fibrosis in children? (Can check more than one answer)
Check all that apply.

   a. Recurrent chest infections with poor response to treatment
   b. Chronic diarrhea
   c. Chronic sinusitis
   d. Persistent vomiting
   e. Failure to thrive
   f. Chronic cough
   g. Persistent wheezing
   h. Frequent hospitalizations
   i. Skin eczema
   j. Chronic abdominal pain
   k. Abdominal distension
   l. Rectal prolapse
   j. Don't know

4- Which of the following are considered a diagnostic tool for cystic fibrosis? (Can check more than one answer)
Check all that apply.

   a. sweat chloride test
   b. blood sodium level
   c. Genetic study
   d. CT-scan chest
   e. Chest x-ray
   f. Renal function test
   g. Stool analysis and culture
   h. Fecal elastase level
   i. Don't know

5- Which of the following scenarios are considered to have a high risk for cystic fibrosis? (Can check more than one answer)
Check all that apply.

   a. 1-year-old boy with intermittent cough and runny nose who has responded very well to inhaled steroids.
   b. 10-year-old girl with chronic productive cough and failure

to thrive and is needed frequent admissions.
c. 5-year-old boy with chronic diarrhea and cough. His brother died at the age of 10 years with a similar illness.
d. 8-year-old girl with recurrent cases of pneumonia and skin rash. She had an allergy to the tuberculosis birth vaccine.
e. Don't know

6- Which of the following considered a therapeutic option for patients with cystic fibrosis? (Can check more than one answer)
Check all that apply.

a. Daily oral antibiotics
b. Inhaled steroid for life
c. Chronic airway clearance using bronchodilators and mucolytics
d. Systemic steroids during the acute exacerbations
e. Multivitamins if the patient has pancreatic involvement
f. Multivitamins and pancreatic enzyme replacement if the patient has pancreatic involvement
g. Inhaled antibiotics daily
h. Inhaled antibiotics during acute flare-ups
i. Regular sputum cultures
j. Follow-up with cystic fibrosis doctor yearly
k. Lung transplantation in the first 5 years of life
l. Gene therapy in the first 10 years if no response to medical therapy m. Treatment of cystic fibrosis acute exacerbation includes intravenous antibiotics and aggressive airway clearance
n. Bone marrow transplantation
o. Don't know

7- Among the following list, choose the likely complications of cystic fibrosis: (Can check more than one answer)
Check all that apply.

a. Chronic bronchiectasis
b. Heart failure
c. Chronic constipation
d. Chronic sinusitis
e. Skin eczema
f. Seizures
g. Chronic renal failure
h. Liver cirrhosis
i. Death if left untreated
j. Pulmonary hypertension
k. Asthma
l. Nasal polyps
m. Gastric cancer
n. Respiratory failure
p. Don't know

8- Which of the following statements are correct? (Can check more than one answer)
Check all that apply.

a. Asthma is a progressive disease and it causes early deaths.
b. Cystic fibrosis can cause a chronic dry cough that is increased at night and with exercise.
c. Asthma and cystic fibrosis are the commonest causes of bronchiectasis.
d. Asthma and cystic fibrosis are the causes of recurrent bronchiolitis in early infancy.
e. Both asthma and cystic fibrosis are inherited diseases.
f. Inhaled steroids are the main treatment for asthma and cystic fibrosis.
g. Inhaled steroids are the main treatment for asthma and not for cystic fibrosis.
h. Don't know

9- What is the mean survival of a patient with cystic fibrosis in Saudi Arabia? (Can check more than one answer)
Check all that apply.

a. Below 20 years
b. 20–40 years
c. Over 40 years
d. Don't know

10- What is the mean survival of patients with cystic fibrosis worldwide?
Check all that apply.

a. Below 20 years
b. 20–40 years
c. Over 40 years
d. Don't know

C- Practice questions

11- Which one of the following patients would you refer to for possible cystic fibrosis specialists? (Can check more than one answer)
Check all that apply.

a. A child with recurrent cough and wheezing that need hospital admission.
b. A child with a chronic productive cough and chronic diarrhea.
c. A child with poor weight gain and recurrent chest infections.
d. A child with recurrent upper respiratory infections.

12- If you have a patient known to have cystic fibrosis comes to your clinic with acute cough and fever and normal oxygen saturation, which of the following options would you do? (Can check more than one answer)
Check all that apply.

a. Refer to a hospital
b. Start oral antibiotics and send home

c. Treat him/her as s/he has an upper respiratory infection with an anti-cough medicine

13- How frequently do you see the children who have cystic fibrosis?

Check all that apply.

a. Once every month
b. Once every 3 months
c. If the patient sick only