

Health Perception and Behaviors in Adults With Bronchiectasis

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BACKGROUND: Bronchiectasis is a chronic debilitating suppurative disease that significantly impacts quality of life. Clinical outcomes like exacerbations, are usually physician centered; however, the patients' experience, health-related behaviors, and expectations have frequently been neglected. In addition, patients' health perceptions may be influenced by their culture. **OBJECTIVE:** To determine the health perception and behavior in adults with bronchiectasis. **METHODS:** We performed semi-directive interviews, which were audiotaped, with 60 adults with bronchiectasis between April 2016 and December 2016. Our interview focused on issues related to symptom perception, access to health-care resources and patient-physician communication, medication adherence, outcomes and expectations, quality of life, and social relationships. **RESULTS:** The subjects with bronchiectasis developed varying patterns of symptom perception (ranging from highly distressing to barely disturbing) and had conflicting opinions on whether and when they should seek health-care services (ranging from active consultations to being totally passive or resistant to seek health care). We observed certain discrepancies between symptom perception and health-related behaviors. Overall, medication adherence was suboptimal, but the subjects were willing to participate in clinical trials and receive complementary alternative medications despite concerns regarding adverse effects of prolonged treatment. There were concerns about the adverse effects of bronchiectasis on fertility and infectiousness to others, although most subjects disregarded these issues. **CONCLUSIONS:** The diverse symptom perception and health-related behaviors highlighted the need for evaluation and intervention in bronchiectasis. These findings will provide rationales for refining future health care through comprehensive (particularly psychological) interventions worldwide. *Key words:* bronchiectasis; perception; medication adherence; quality of life; cost of illness. [Respir Care 2019;64(4):462–472. © 2019 Daedalus Enterprises]

Introduction

Bronchiectasis is not an orphan lung disease.¹⁻⁶ The most prominent symptoms of bronchiectasis are chronic

cough and production of mucopurulent or purulent sputum, followed by hemoptysis, fatigue, or dyspnea. Recurrent airway infections can result in exacerbations associated with increased health-care costs and poor quality of life. Despite greater awareness and improvement in research efforts, the management of bronchiectasis has been

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hampered by a lack of understanding of the pathogenesis and effective medications. The mortality remains considerably high.^{4,7,8} Globally, management of bronchiectasis is multidimensional,^{7,9} but the evidence to guide therapeutic decisions remains scarce. This is particularly true in China where the etiologic spectra remain largely unclear, although cystic fibrosis is unlikely the common underlying cause.

Bronchiectasis confers significant adverse impacts. Nocturnal productive cough impairs sleep quality,¹⁰ which results in anxiety and depression¹¹ associated with impaired quality of life.¹⁰ Frequent exacerbation is a risk factor for mortality.¹² Although clinical trials have mostly focused on well-established end points (ie, exacerbations,^{13,14} bacterial load,¹⁵ and airway inflammation¹⁶), many important patient-centered outcomes have frequently been neglected. Identification of these critical issues may complement current disease management. A lack of information and self-efficacy is an obstacle to self-management of bronchiectasis.¹⁷ The balance between barriers and motivation can affect adherence to treatment.¹⁸ Social embarrassment, sleep disturbance, anxiety, and modification of daily and future activities may lead to significantly impaired quality of life in individuals with bronchiectasis.¹⁹ In addition, information deficits may constrain self-management in individuals with bronchiectasis.²⁰ Nonetheless, little is known regarding health perception and behaviors in patients with bronchiectasis, apart from self-management in developing countries where the cultural background may be different.

Bronchiectasis management in China has not been well documented. There have been notable differences in the health-care system compared with developed countries. In China, the lack of a system for triage to different levels of care has been attributed to direct consultation in tertiary hospitals. The immense work load has resulted in burnout of health-care staff because they do not have enough time to be engaged in patient health-care education. Physicians in China are often not as respected as in other countries. Despite progress in health-care reform, health education remains largely deficient, particularly in rural areas. Patients seek health care inconsistently, and their adherence to medication or treatment may be suboptimal. In many primary health-care settings, traditional Chinese medicine remains the preferred therapeutic option. A better understanding of health perception and behavior could be

QUICK LOOK

Current knowledge

Bronchiectasis is a chronic debilitating airway disease that contributes to significantly impaired quality of life. Health perception and behaviors, the mostly neglected aspects of bronchiectasis management, seemed to be highly diversified in recent literature reports.

What this paper contributes to our knowledge

Subjects with bronchiectasis demonstrated diverse symptom perception and health-related behaviors. Improved knowledge regarding symptom perception and health-related behaviors addresses the clinical need to more comprehensively assess and manage bronchiectasis. This research is important given the previously neglected aspects of patient evaluation (particularly quality of life), which usual center on the effectiveness of conventional treatment.

achieved via improved communication with patients with bronchiectasis. We conducted interviews that specifically focused on perception and behaviors in subjects with bronchiectasis. We highlighted neglected, but important, issues related to bronchiectasis: impact on fertility, traditional Chinese medicine, expectations of development of novel medications, and willingness to participate in clinical trials.

Methods

Subject Recruitment

Sixty subjects with bronchiectasis were recruited between April and December 2016. To represent real-world practice, we selected a convenience sample from the outpatient clinics of The First Affiliated Hospital of Guangzhou Medical University. Eligible patients were ages 18–75 y and had bronchiectasis diagnosed by high-resolution computed tomography within the previous 12 months.¹⁶ Exclusion criteria were patients with language barriers and participation in clinical trials within the past 3 months. Disease severity was assessed with the Bronchiectasis Severity Index (0–4, 5–8, and ≥ 9 points denoted mild, moderate, and severe bronchiectasis, respectively). The ethics committee of The First Affiliated Hospital of Guangzhou Medical University gave approval. The subjects gave written and verbal consent before the interview. The flow chart of subject recruitment is shown in Figure 1.

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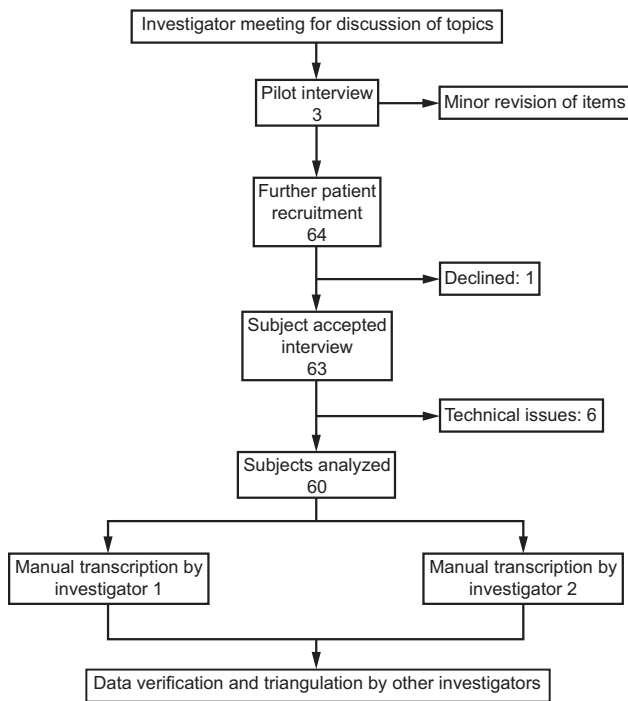


Fig. 1. Flow chart. Technical issues included both complete and partial loss of audio files.

Study Design and Data Generation and Analysis

An investigators' meeting (all members) was held to discuss key questions related to subjects' perception and management of bronchiectasis and, subsequently, formulated the scheduled interviews. The research nurse (HML) invited consecutive patients to participate, whereas 4 investigators (WJG, JJY, YH, CLC) organized interviews. Willing subjects received an informational letter and selected an available time for participation. A structured schedule of given topics was used to guide the semi-directive interview. Interviews were conducted in a private room, with audio recording. The subjects were encouraged to communicate freely by using Mandarin or Cantonese), and each interview lasted between 30 and 60 min.

Contents of the interview were recorded for transcription of subject's statements into an electronic database. Four pre-determined categories were formed: (1) symptom perception; (2) access to health-care resources and patient-physician communication; (3) medication adherence, outcomes, and expectations; and (4) quality of life and social relationships. We performed a pilot interview with 3 subjects, followed by a debriefing, which entailed identification of norms and conflicting viewpoints. We made minor revisions after analysis of audio records by adding a question regarding the subject's willingness to participate in clinical trials (to investigate whether the subjects would deem participation in clinical trials acceptable according to Chinese culture and their own beliefs).

Subsequent interviews were performed according to the modified topics (Table 1). After familiarization with the audio recordings and a notes review, an investigator (WJG) manually transcribed the records, followed by selective coding. We compared responses across individuals, followed by data rearrangement and framework development into 4 main categories. We investigated the subjects' willingness to seek health care (not every subject initially sought consultation in primary facilities or be bound to a fixed tertiary hospital), subjects' self-assessment of treatment outcomes of traditional Chinese medicine, adverse effects of medications, and the impact of bronchiectasis on quality of life not disclosed previously (eg, fertility, exercise). Matrices were generated to demonstrate the main themes. Other investigators (JJY, HML, YH, CLC, YHG, RCC and NSZ) verified the main and subcategories via a follow-up questionnaire. One investigator (WJG) translated records into English for manuscript drafting and performed statistical analysis by using GraphPad Prism 5.0 (GraphPad, La Jolla, California). Transcripts that represented common summary comments and/or opinions or that contained sufficient information and/or interpretation for the statements are presented.

Results

Subject Characteristics

Sixty subjects were finally included for data analysis. The mean age was 49.1 y, 56.7% females, and 91.7% never-smokers. The mean Bronchiectasis Severity Index was 5.9 (Table 2). Categories and subcategories are shown in the supplementary material (see the supplementary materials at <http://www.rcjournal.com>). Representative responses to interview questions are presented in Tables 3–6.

Symptom Perception

Recurrent cough, followed by sputum production, was the most bothersome symptom.

- “Only when it [the sputum] was coughed up that I would feel comfortable. . . . I would immediately cough it out when I've got the phlegm” (subject no. 23: female, age 50 y).

Most subjects had experienced hemoptysis; however, attitudes toward management were conflicting. Most patients actively sought health care in the case of hemoptysis.

- “Coughing up blood was sometimes troublesome. . . . I would always immediately go to the hospital for medication once I coughed up blood” (subject no. 43: male, age 35 y).

Table 1. Interview Contents for Adults With Bronchiectasis

Interview Contents
Symptom perception
Which symptom bothered you most, and how did it affect your quality of life?
Have you ever coughed up blood (including bloody sputum)? How did you manage it accordingly?
Do you cough up sputum frequently outside your house? How did you manage it (ie, wrap up the phlegm in tissues, cough up in washrooms, spit elsewhere)?
Access to health-care resources and patient-physician communication
To what extent would you be willing to actively seek medical care? Do you think it is appropriate to withdraw from treatment after symptoms are resolved? Why?
What is the major barrier limiting access to medical care? Expenditure, time, or difficulty in registration?
How long did physicians spend on inquiring about your symptoms on average during out-patient clinics? Did physicians sufficiently inform you of relevant information?
Do you think bronchiectasis constitutes a significant economic burden? Have you declined to seek medical care due to economic issues? Why?
Did your attending physician(s) inform you of having other concomitant diseases (ie, asthma, chronic obstructive pulmonary disease, hypertension)? How did these disorders affect bronchiectasis? Why?
Treatment adherence, outcomes, and expectations
Have you been fully adhered to medication treatment? Do you think other approaches (ie, traditional Chinese medicine, physical therapy) could replace conventional medications?
What do you think about the overall efficacy of the current treatment? Do these medications work equally well in other respiratory diseases (ie, chronic obstructive pulmonary disease, asthma)?
Do you have concerns of the adverse effects of medications for bronchiectasis? Why?
Which major symptom do you think that future treatment should primarily target? What would be the optimal route of administration (oral, inhaled, intravenous)?
Would you be willing to participate in clinical trials on bronchiectasis? Why?
Quality of life and social relationship
What was your family member's attitude toward you? Have you received support from your family? Have you better managed bronchiectasis through attending activities (looking after children, doing housework)?
What other social members (including your friends, colleagues) think about you? Were you treated differently because of cough or expectoration in the public?
Do you think bronchiectasis would affect your sleep quality? How did you manage bronchiectasis symptoms to sleep better?
Have you shared the experience of managing bronchiectasis with others who had the same illness? Do you need to seek support from the community of patients with bronchiectasis?
Do you think you can perform physical exercises? If so, what would be your maximum tolerable exercise? If not, why?
Have you given birth to a child? If not, do you think bronchiectasis affects fertility? If yes, has bronchiectasis affected the health of your child?
Do you think bronchiectasis is hereditary?
Do you think bronchiectasis could be transmitted to others (ie, sons, daughters, grandsons, granddaughters)?

Access to Health-Care Resources and Subject-Physician Communication

Early management might improve long-term outcomes; however, the subjects were ambivalent to seeking health care. Most subjects immediately sought health care when they experienced discomfort, whereas some came for regular medication refills.

- “I would see the doctor when coughing up blood or having a lot of phlegm . . . and will take [medications] if doctors prescribed them” (subject no. 32: female, age 20 y).

But some preferred delayed hospital visits.

- “I seldom [go to the hospital] . . . because if I have fever . . . I've got medicine at home . . . but I would [go to the

hospital] when I felt it became severe enough” (subject no. 28: male, age 53 y).

Importantly, only half frequently withdrew medications once symptoms were alleviated.

- “Sometimes I would skip taking some [medications] when I am feeling slightly better” (subject no. 44: female, age 46 y).

Most subjects commented that self-management was effective.

- “I would do some farming, take a walk, or play some cards . . . to distract myself [from bronchiectasis].” (subject no. 46: male, age 67 y).

Perception of disease burden varied, but most subjects rated their monthly expenditure as low or moderate. To

Table 2. Clinical Characteristics of Participants Finally Included in the Interview

Parameter	Results
Anthropometry	
Age, mean \pm SD y	49.1 \pm 13.6
Height, mean \pm SD cm	161.9 \pm 8.2
Body mass index, mean \pm SD kg/m ²	20.7 \pm 3.4
Females, n (%)	34 (56.7)
Never-smokers, n (%)	55 (91.7)
Disease characteristics	
Duration of bronchiectasis symptoms, y	16.0 (18.2)
Exacerbation frequency within 1 year, times/person	1.0 (2.0)
No. of bronchiectatic lobes, n	4.0 (2.0)
HRCT total score, mean \pm SD	8.5 \pm 4.0
Bronchiectasis Severity Index score, mean \pm SD	5.9 \pm 3.5
Bronchiectasis etiology, n (%)	
Idiopathic	25 (41.7)
Post-infectious	21 (35.0)
Other known etiologies	14 (23.3)
Sputum bacteriology, n (%)	
<i>Pseudomonas aeruginosa</i>	21 (35.0)
Other pathogenic bacteria*	14 (23.3)
Commensals†	25 (41.7)
Comorbid diseases, n (%)	
Rhinosinusitis	24 (40.0)
Others‡	3 (5.0)
Subjects who used medications within 6 mo, n (%)	
Mucolytics	45 (75.0)
Macrolides	25 (41.7)
Inhaled corticosteroids	20 (33.3)

N = 60. Continuous variables are presented as mean \pm standard deviation for data with normal distribution, or median (interquartile range) for data with non-normal distribution, respectively. The data with the parenthesis for "Disease characteristics" denoted those with non-normal distribution.

None of the subjects was using inhaled or oral antibiotics at the time of the study.

* *Haemophilus influenzae*, *Haemophilus parainfluenzae*, *Klebsiella* species, *Escherichia coli*, *Proteus mirabilis*; other known etiologies included immunodeficiency (n = 7), gastroesophageal reflux disease (n = 2), asthma (n = 1, clinically stable), cystic fibrosis transmembrane regulator-associated disorder (n = 1), diffuse panbronchiolitis (n = 1), Kartagener syndrome (n = 1), lung mal-development (n = 1).

† *Neisseria*, *α -Streptococcus hemolyticus*, *Bacilli diphtheria*, and coagulase-negative *Staphylococcus*.

‡ Included hypertension (n = 1 [1.7%]), hepatitis (n = 1 [1.7%]), and primary aldosteronism (n = 1 [1.7%]). A minor proportion of subjects was deemed as having dual etiologies; therefore, the total percentage of individual etiology slightly exceeded 100%.

HRCT = high-resolution computed tomography

most subjects, the economic burden did not constitute a major barrier for seeking health care.

In China, the subjects sometimes seek health care in tertiary hospitals without referral. Despite this, most subjects commented that attending long-term follow-up visits was challenging. Reasons included "costly," followed by "a long wait time," and the "difficulty in registration." In clinics, the median duration of consultation was 10 min per subject. Most subjects were satisfied with physician's

provision of information for bronchiectasis management in tertiary hospitals, whereas others felt dissatisfied.

- "It seemed that, apart from symptom inquiry and prescription of medicine . . . they [doctors] had said nothing else" (subject no. 8: female, age 45 y).

Medication Adherence, Outcomes, and Expectations

Subjects' attitudes toward treatment were diverse. First, most subjects were adherent to maintenance therapy (self-reported use of macrolides, mucolytics, chest physiotherapy, inhaled bronchodilators), whereas the remaining subjects administered therapy intermittently (during exacerbations and/or colds, or when having hemoptysis). Second, Western medications were mostly used for maintenance or intermittent treatment. We asked the subjects whether traditional Chinese medicine could substitute for Western medications, and a few gave completely positive comments. Importantly, approximately one fifth of the subjects commented that both types of medications were complementary and might add to current treatment. Most subjects gave ambiguous responses because they had never been prescribed traditional Chinese medicines.

- "We can combine [the effects of traditional Chinese medicine and Western medicine]. . . . That is, traditional Chinese medicine mainly may help supplement the treatment" (subject no. 27: female, age 66 y).
- Treatment outcomes are dependent on medication adherence.¹⁸ We asked the subjects to provide global self-assessments or ratings of their previous therapeutic outcomes. More than half were rated as satisfactory, followed by moderate and poor. Positive responses included "Overall satisfactory, but I don't know whether it [bronchiectasis] may get healed" (subject no. 52: female, age 68 y), whereas negative responses included "Based on my previous experience [on the effects], the overall outcomes were not good. . . . It seemed that there is no difference whether I take the medications or not [on managing coughing up blood]" (subject no. 20: male, age 75 y). For most subjects, therapeutic outcomes of bronchiectasis resembled those of COPD.

Half of the subjects showed concern about adverse effects of treatment, mostly related to gastrointestinal problems and frailty.

- "When taking medications, I felt my hands trembling and felt fatigued, which were ameliorated after withdrawal [of medications]" (subject no. 45, male, age 37 y).

Despite this, most subjects expected that novel medications would resolve excessive coughing and sputum

HEALTH PERCEPTION AND BEHAVIOR IN BRONCHIECTASIS

Table 3. Symptom Perception

Interview Question	Response	Subject Comments
Predominant symptom and impact	Agreed	“I kept coughing everyday” (subject no. 51: female, age 43 y)
		“Only when it [the sputum] was coughed up that I would feel comfortable. . . . I would immediately cough it out when I’ve got the phlegm” (subject no. 23: female, age 50 y)
	Disagreed	“I sometimes felt short of breath when doing housework or during exertion” (subject no. 14: male, age 35 y)
Management of hemoptysis	Active	“My symptoms are not prominent and my daily life has not been affected.” (subject no. 60: male, age 43 y)
	Disregarded	“Coughing up blood was sometimes troublesome. . . . I would always immediately go to the hospital prescribing medication once I coughed up blood.” (subject no. 43: male, age 35 y)
Management of sputum production	Formal	“I am simply not bothered and took no action [when coughing up blood]” (subject no. 31: male, age 50 y)
	Casual	“I would cough up [phlegm] in the toilet in the morning or in the trash can at night.” (subject no. 09: female, age 43 y)
		“Sometimes I had to spit beside trees [on the sidewalk] when I’m [walking] on the street.” (subject no. 46: male, age 67 y)

Table 4. Access to Health-Care Resources and Subject-Physician Communication

Interview Question	Response	Subject Comments
Willingness to seek health care	Active	“I would see the doctor when coughing up blood or having a lot of phlegm . . . and will take [medications] if doctors prescribed them.” (subject no. 32: female, age 20 y)
	Passive	“I seldom[go to the hospital] . . . because if I have fever . . . I’ve got medicine at home . . . but would [go to the hospital] when I felt it became severe enough” (subject no. 28: male, age 53 y)
Major barrier limiting access to health care	Duration	“The main issue is time . . . and I live somewhat far away [from the hospital].” (subject no. 39: female, age 48 y)
	Registry	“Sometimes it’s difficult to even get registered [for consultation]” (subject no. 26: male, age 37 y)
Duration of physician consultation	Short	“6–7 min” (subject no. 34: female, age 57 y)
	Moderate	“some 10 min” (subject no. 36: male, age 42 y)
Physician’s provision of knowledge	Sufficient	“The time to describe my symptoms and for the doctors to offer consultation . . . [hesitated a while] usually takes about 10 min” (subject no. 14: male, age 35 y)
	Insufficient	“Doctors here [in tertiary hospital] have informed me with sufficient information on my conditions.” (subject no. 18: male, age 50 y)
Concomitant disease and impact	Upper airway	“It seemed that, apart from symptom inquiry and prescription of medication, and then . . . they [doctors] had said nothing else” (subject no. 8: female, age 45 y)
	Lower airway	“I’ve got rhinosinusitis . . . it has moderate negative effects because it might worsen my bronchiectasis [is linked through the respiratory tract].” (subject no. 41: male, age 24 y)
	Systemic	“I have chronic obstructive pulmonary disease. . . . It quite affects my bronchiectasis. Although I keep taking the medicines, it [chronic obstructive pulmonary disease] has made my bronchiectasis more severe” (subject no. 11: female, age 69 y)
		“I have hypertension. . . . I felt that it was not associated with my bronchiectasis.” (subject no. 33: female, age 65 y)

production. Both oral and inhalation are preferred routes. Privacy is probably the main reason that drove some subjects’ preference to inhalation therapy.

- “I prefer oral medications because they are the most convenient . . . inhalation should be done privately and devices are needed for intravenous injection” (subject no. 21: male, age 39 y).

Finally, most subjects were willing to participate in clinical trials, whereas a minority of the subjects explicitly rejected participating.

- “With pleasure, I would participate, because I think that since I’ve got it [bronchiectasis], and current medical science and medications are not effective, the investigators would strive to make ongoing improvement. So

Table 5. Treatment Adherence, Outcomes, and Expectations

Interview Question	Response	Subject Comments
Adherence	Positive	"I have been taking whatever [medications] the doctors prescribed" (subject no. 48: female, age 22 y)
	Negative	"Sometimes I would skip taking some [medications] when I am feeling slightly better" (subject no. 44: female, age 46 y)
The role of TCM and other therapies	Positive	"In some sense, I do recognize the role of TCM on [treating] my disease [bronchiectasis]" (subject no. 20: male, age 75 y)
	Complementary	"We can combine [the effects of TCM and Western medicine]. . . . That is, TCM mainly may help supplement the treatment" (subject no. 27: female, age 66 y)
	Negative	"TCM cannot replace Western medicine." (subject no. 35: male, age 38 y)
Treatment outcomes	Positive	"Overall satisfactory, but I don't know whether it [bronchiectasis] can be cured" (subject no. 52: female, age 68 y)
	Neutral	"Frankly speaking, I think the overall outcome is modest" (subject no. 35: male, age 38 y)
	Negative	"Based on my previous experience [on the effects], the overall outcomes were not good. . . . It seemed that there is no difference whether I take the medications or not [on managing coughing up blood]" (subject no. 20: male, age 75 y)
Concerns of adverse effects	Positive	"When taking medications, I felt my hands trembling and felt fatigued, which were ameliorated after withdrawal [of medications]." (subject no. 45: male, age 37 y) "I felt that I would be addicted and rely too much on medications upon prolonged use." (subject no. 49: male, age 59 y)
	Neutral	"For now I have not felt any [of the adverse effects] except for the . . . antibiotics. . . . [Because] I would have poor sleep upon taking it [antibiotics]." (subject no. 30: female, age 54 y)
	Negative	"There are no adverse effects at the moment." (subject no. 13: male, age 45 y)
Target for future medicine	Inhaled	"Inhaled [medicine] is better in helping me expel, it [the sputum] would come out easier" (subject no. 37: female, age 63 y)
	Oral	"I prefer oral medications because they are the most convenient . . . inhalation should be done privately; devices are needed for intravenous injection." (subject no. 21: male, age 39 y)
	Intravenous	"[I prefer] intravenous [injection]. . . . It [bronchiectasis] got better more rapidly, say generally 1 to 2 days, but it would take 5 or 7 days when treated with oral [medications]." (subject no. 29: male, age 25 y)
Willingness to participate in clinical trials	Positive	"With pleasure, I would participate, because I think that since I've got it [bronchiectasis], and current medical science and medications are not effective, the investigators would strive to make ongoing improvement. So why shouldn't we take a chance?" (subject no. 21: male, age 39 y)
	Neutral	"[The clinical trial] should not be too burdensome [to me] . . . I would need that the novel medication that can improve my symptoms to be an oral medication." (subject no. 13: male, age 45 y)
	Negative	"My son asked me not to participate [in clinical trials] . . . I myself am not inclined to take part as well, especially, if based on the current status, which is not severe enough." (subject no. 03: female, age 59 y)

why shouldn't we . . . have a try?" (subject no. 21: male, age 39 y).

- Some subjects took the wait-and-see attitude.
- "[The clinical trial] should not be too burdensome [to me]. . . . I would need the novel medication that can improve my symptoms to be an oral medication" (subject no. 13: male, age 45 y).

Quality of Life and Social Relationships

Family support was crucial to the subjects. Among most subjects, family members offered more support since their clinical diagnosis. Symptoms might elicit embarrassment: most subjects felt that they were treated as healthy, but some friends or relatives might not have been aware that

they had bronchiectasis. However, some subjects did face public stigma.

Subjects held different views regarding participation in support groups where ideas and/or experience could be shared. Although no such organization exists in China, most were willing to participate, whereas some directly declined.

- "I look forward to having such communities to help alleviate the psychological impact and pressure bronchiectasis has had on me" (subject no. 41: male, age 24 y).
- "I myself was skeptical on whether the doctors are prescribing the right medication to [help] my symptoms, let alone other patients." (subject no. 20: male, age 75 y).

HEALTH PERCEPTION AND BEHAVIOR IN BRONCHIECTASIS

Table 6. Quality of Life and Social Relationship

Interview Question	Response	Subject Comments
Family support	Supportive	"They [the family members] would try to persuade me to stop smoking and ask me to do more exercises." (subject no. 15: male, age 58 y)
	Neutral	"My parents would not pay particular attention [to my disease] because it is not severe enough. . . . None of my friends even knew I've got the disease [bronchiectasis]." (subject no. 45: male, age 37 y)
Self-management	Useful	"I would do some farming, take a walk, or play some cards . . . to distract myself [from bronchiectasis]." (subject no. 46: male, age 67 y)
	Neutral	"I can still manage my normal daily life." (subject no. 41: male, age 24 y)
	Useless	"I felt restless, and found myself being somewhat anxious. It takes a long time to perform task . . . sometimes I would be worried and come to see the doctor. . . . But I do forget to take my medications quite often." (subject no. 52: female, age 68 y)
Social support	Supportive	"They are supportive and would not treat me differently" (subject no. 01: female, age 37 y)
	Neutral	"They would still play cards with me everyday" (subject no. 33: female, age 65 y)
	Unsupported	"I have never dared to tell anyone [about bronchiectasis]. . . . None of my colleagues knew that I've got bronchiectasis . . . but they would often ask how am I doing and why do I kept coughing. . . . I simply responded to them that I've caught a cold. . . . I do feel they did treat me differently." (subject no. 41: male, age 24 y)
Impact on sleep quality	Poor but manageable	"Sometimes I would cough all the way till I wake up in morning . . . if I had light diet in the day I would seldom cough at night. . . . I would get up to boil up some soup to drink" (subject no. 23: female, age 50 y)
	Poor but not manageable	"I got lots of phlegm the moment I lie on bed at night. . . . I often sleep poorly while napping at noontime. When I felt discomfort from the phlegm I will cough it up" (subject no. 43: male, age 35 y)
		"Yes, it [bronchiectasis] affected my sleep. . . . I became fatigued because I cannot have a good sleep at night. . . . I would intentionally had dinner and did [postural] drainage earlier each night, and thought that this would make me sleep better, but it still failed, and I would still get up all night to expel the phlegm" (subject no. 11: female, age 69 y)
	Minimal	"I can have a good sleep at night. It [bronchiectasis] did not affect my sleep except during exacerbations." (subject no. 29: male, age 25 y)
Joining clubs and sharing information	Positive	"I look forward to having such communities to help alleviate the psychological impact and pressure bronchiectasis had on me" (subject no. 41: male, age 24 y)
	Neutral	"Well, it is human nature, you know . . . we do have a sense of the so-called self-protection. . . . In my opinion, the Chinese people do not wish others to know much about such things [private matters]" (subject no. 35: male, age 38 y)
	Negative	"I myself was skeptical on whether the doctors are prescribing the right medication to [help] my symptoms, let alone other subjects." (subject no. 20: male, age 75 y)
Physical exercise	Walking	"I can walk up to 3 hours after dinner." (subject no. 16: female, age 47 y)
	Jogging	"I do not have much time to exercise, but I can jog for a little while." (subject no. 34: female, age 57 y)
	Other means	"I could play badminton about thrice weekly and would also do some hiking." (subject no. 05: male, age 26 y)
	"Sometimes, I would do square dancing when I am back in my hometown . . . but I cannot do jogging." (subject no. 33: female, 65 y)	
	"Since I moved to the 9th floor I have only gone for Tai Chi twice." (subject no. 52: female, age 68 y)	
	"I seldom [did exercise] . . . mostly just some walking and jogging. . . . At most [I could] jog for 15 min . . . because it felt tiring to do all these" (subject no. 44: female, age 46 y)	
Fertility	Minor impact	"I have been afraid of this [infertility], I do have a slight fear that my children would inherit the disease" (subject no. 32: female, age 20 y)
	Unknown	"I am divorced . . . had rarely thought of this [issue]" (subject no. 14: male, age 45 y)
	Adverse impact	"I think that it [bronchiectasis] affects fertility. . . . Coughing led to a miscarriage during my previous pregnancy." (subject no. 54: female, age 39 y)
Infectiousness	No impact	"For now [I believe that] it [bronchiectasis] would be transmitted to my children, but [I'm] not sure if bronchiectasis is hereditary" (subject no. 19: male, age 59 y)
	Unknown	"I do fear that it [bronchiectasis] can be transmitted to others although it is said not to be . . . what if it really can be transmitted then it will be bad" (subject no. 03: female, age 59 y)
	Adverse impact	"I do worry that it [bronchiectasis] may be infectious." (subject no. 56: male, age 74 y)

TCM = traditional Chinese medicine

Most subjects stated that bronchiectasis negatively affected sleep quality, particularly during exacerbations.

- "I got lots of phlegm the moment I lay in bed at night. . . . I often sleep poorly while napping at noontime. When I felt discomfort from the phlegm I will cough it up" (subject no. 43: male, age 35 y).

Major methods for dealing with disturbed sleeping included drinking some water and coughing up phlegm.

Most subjects could exercise to different extents. But some attempted to avoid exercise.

- "I seldom [exercise] . . . mostly just some walking and jogging. . . . At most [I could] jog for 15 min . . . because it felt tiring to do all these" (subject no. 44: female, age 46 y).

Of all exercises, walking was preferred, yet others preferred Tai Chi, playing badminton, or square dancing (which is popular in China).

- “I can walk up to 3 hours after dinner” (subject no. 16: female, age 47 y).

Since implementation of the 2-child policy in China, more families planned to have another child. We inquired about subjects’ views of fertility associated with bronchiectasis. Most had a child and showed no concern of negative impacts on fertility, although some did.

- “I think that it [bronchiectasis] affects fertility. . . . Coughing led to a miscarriage during my previous pregnancy” (subject no. 54: female, age 39 y).
- Most subjects believed that bronchiectasis would not affect their children, but suspicion was raised “when my mother was diagnosed as having bronchiectasis” (subject no. 07: female, age 45 y).

Most subjects believed that bronchiectasis was not hereditary.

- “For now [I believe that] it [bronchiectasis] would not be transmitted to my children, but [I’m] not sure if bronchiectasis is hereditary” (subject no.19: male, age 59 y).

Finally, most subjects commented that they had no worries about potential infectiousness.

- “We value hygiene pretty much. . . . Though we share dishware together, we have a disinfection cabinet, and sometimes [we also disinfect] using boiling water” (subject no. 33: female, age 65 y).

Discussion

This study extended findings on self-management of bronchiectasis.¹⁷ The diverse symptom perceptions that we encountered echoed the recent findings of highly individualized bronchiectasis symptoms.¹⁸ In some patients, hemoptysis carries substantial psychological burden and could be the leading drive for seeking health care.²¹

The subjects with bronchiectasis had conflicting opinions on whether and when they should seek health care. There was a discrepancy between symptom perception and behaviors. The underlying causes may be multifaceted, including the health-care system, cost associated with bronchiectasis management, the need to balance symptom burden, perceived barriers to seek health care, and the intrinsic motivation to opt for better therapeutic outcomes. Although most subjects perceived themselves as living normally, they sought to protect themselves by suppressing the manifestation of symptoms (eg, frequent or massive sputum expectoration) or by concealing their diagnosis from others. Self-efficacy may help explain that these subjects tended to feel competent when performing different tasks.²²

Overall medication adherence was suboptimal, and concerns regarding adverse effects still exist. We found that subjects’ medication adherence was associated with their own beliefs, trust in health-care professionals, treatment response, and acceptance of the disease and treatment.¹⁸ Therefore, the barriers and limited motivation to seek health care in some subjects may help inform the suboptimal medication adherence. Of potential barriers to self-manage bronchiectasis, information deficits could be addressed by providing health-care information and by improving physician-patient communication.²⁰ As addressed in our previous work,²³ medication adherence correlated significantly with long-term outcomes.

Intriguingly, symptom perception may be collectively shaped by socioeconomic status, treatment outcomes, and previous interactions with physicians. For instance, because of “the difficulty in registration,” “the costs,” inadequate disposition by attending physicians,” and “potential side effects of medications,” many subjects were reluctant to seek health care until significant symptom aggravation, which rendered routine follow-up challenging. Nonetheless, because most subjects recognized the limitations of currently available treatment, they remained open to clinical trials with novel medications or supplementation with traditional Chinese medicine although it was never prescribed. Both oral and inhaled medications seemed to be well accepted by most of the subjects, which reflected the subjects’ expectancy and value of treatment strategies.

In real-world practice, many subjects in China directly sought health care from tertiary hospitals, with unrealistic expectations of a complete cure for their bronchiectasis. The stark contrast with actual outcomes might have led to frustration after exhaustive consultations with physicians, and the growing dissatisfaction and/or mistrust with medicine could result in non-adherence. This may be compounded by the insufficient time for consultation at clinics, where physicians are frequently overwhelmed by their daily work load. Although many developed countries have medical systems that differ from those in China, our findings might apply in many other developing countries where health-care resources are largely insufficient. A practical implication is that addressing unmet medical needs could be achieved via improving physician-patient communication and patient health education. Understanding the factors that impair quality of life may complement medication treatment via cognitive therapy that could help patients establish appropriate perceptions of their health, alleviate social embarrassment, and ameliorate anxiety and depression.

Despite mostly sufficient family support, the subjects still had impaired quality of life and sought to distract themselves from bronchiectasis. Most subjects were not concerned that bronchiectasis could reduce their fertility or that bronchiectasis might be hereditary. However, some subjects had major anxiety and depression. Therefore, physicians should remain vigilant to psychological interventions

at clinics. These clinical questions, along with European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) Clinical Research Collaboration document,²⁴ were previously highlighted as research priorities.²⁵

This study was limited by the generalizability to other health-care settings worldwide^{17,26} because of the single-center study setting. Provision of an informational letter to willing participants would better identify additional ethical considerations. Translation of Chinese into English might inevitably result in information loss. Despite these limitations, many findings were universal issues regarding global bronchiectasis management, as evidenced by the commonality reported in recent literature from Europe.¹⁷⁻¹⁹ Diverse health perceptions and behaviors, and factors that influence quality of life in bronchiectasis echo the findings of recent studies from developed countries.¹⁷⁻¹⁹ Our study addressed many neglected but critically important issues in real-world practice, particularly in Asian countries where bronchiectasis investigation remains largely insufficient.

Therefore, some findings related to the local culture might better reflect real-world practice in many developing countries where bronchiectasis management has not been sufficiently documented. The present study provided further support for the likelihood that patients respond across the spectrum of behaviors and beliefs. For clinical management of bronchiectasis worldwide, building on coping mechanisms that work for each individual might lead to improved disease self-management or quality of life. Finally, this study confirmed that responses of Chinese adults with bronchiectasis echoed subjects from other cultures; therefore, interventions found useful in other countries (when tailored to the Chinese health-care system and cultural norms) might help to guide clinical trials in China.

Conclusions

The subjects with bronchiectasis developed various symptom perceptions from highly distressed to barely disturbed and had conflicting opinions on whether and when they should seek health-care services (from active consultations to being totally passive or resistant). These findings could help health-care staff and policymakers become aware of disease burden and better meet the needs of patients with bronchiectasis worldwide.

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