

The impact and financial burden of pulmonary arterial hypertension on patients and caregivers: results from a national survey

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Abstract

Pulmonary arterial hypertension (PAH) is a chronic progressive devastating disease. Symptom burden might impair health-related quality of life of patients. Furthermore, treatment on this disease brings significant financial burden to patients' families. Both physiological and psychological symptoms have been reported, but limited evidence regarding the impact of PAH on patients and caregivers exists, especially the emotional issues and their association with patients' health quality. The main purpose of this study was to describe the impact of PAH on patients and their caregivers in a Chinese population.

This large-scale national survey enrolled 174 participants to complete questionnaires using face-to-face semistructured interviews.

PAH influenced all aspects of patients' lives including daily activities, work, emotions, and personal relationships. Both patients and caregivers reported a major impact on family finances and on their work. The majority of patients had feelings of isolation. A lack of public understanding about PAH contributes to social isolation. Most patients and caregivers would like to get information regarding PAH doctors and patient organization contacts to obtain support.

This survey-based report provides information regarding the way and extent to which PAH impacts both patients and their caregivers and provides some means for comparison with non-Chinese populations. It is important for physicians and the community to offer more support and information for PAH patients and their families.

Abbreviations: CTDPAH = connective tissue disease-associated pulmonary arterial hypertension, FC = functional class, HRQOL = health related quality of life, IPAH = idiopathic pulmonary arterial hypertension, mPAP = mean pulmonary artery pressure, PAH = pulmonary arterial hypertension, PAWP = pulmonary artery wedge pressure, PH = pulmonary hypertension, QOL = quality of life, WHO = World Health Organization.

Keywords: caregivers, patients, pulmonary arterial hypertension, quality of life, survey

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ZZ designed the questionnaire used in this study, drafted and revised the manuscript. XZ and SZ participated in data collection and statistical analysis, and revised the manuscript. WX, JW, and TK participated in the design of the study and performed the statistical analysis. HH participated in the design of questionnaires and the organization of the survey. YY and CW conceived of the study, and participated in its design and coordination and helped to draft the manuscript. All authors read and approved the final manuscript.

ZZ, XZ, and SZ contributed equally to this article.

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1. Introduction

Pulmonary arterial hypertension (PAH) is a chronic and devastating disease characterized by progressively increasing pulmonary vascular resistance that results in an elevated mean pulmonary artery pressure (mPAP).^[1,2] Epidemiological data for PAH are limited because of low disease prevalence. According to a retrospective cohort study from China, 1- and 3-year survival estimates were 92.1% and 75.1%, respectively, in patients with idiopathic pulmonary arterial hypertension (IPAH), and 85.4% and 53.6%, respectively, in patients with connective tissue disease-associated pulmonary arterial hypertension (CTDPAH). Though survival improved, PAH still imposes enormous burden in Chinese patients.^[3]

Symptoms of PAH include dyspnoea, fatigue, chest pain, syncope, and peripheral oedema, and such symptoms impair the daily activity capacity of PAH patients. If untreated, some patients experience consistent dyspnoea and fatigue with disease progression, finally leading to right heart failure and death. With various new treatment options, the long-term prognosis of PAH has significantly improved. Recent registries of PAH patients showed improved data with a 3-year survival of <83% with advanced therapies.^[4] However, none are curative.^[5] Patients with PAH have a significant multifactorial symptom burden that impairs quality of life (QOL) and probably continues even with optimal PAH therapy.^[6]

Current therapy may have a positive impact on the functional status and QOL, which must be evaluated independently. Both physiological and psychological symptoms have been reported in previous studies. Anxiety, depression, panic attacks and panic disorders were most commonly reported.^[7] Nevertheless, limited evidence regarding the impact of PAH on patients and caregivers exists, especially emotional issues for PAH patients and their association with patients' quality of life. Concerns regarding intimacy are another issue frequently reported by patients and partners, but no respective research has been conducted.

Previous work had studied the impact of PAH on the lives of patients and caregivers,^[2,8,9] but relatively limited research focuses on the broader impact of PAH on the lives of Chinese patients and their caregivers. Whether Chinese PAH patients and their caregivers are at the similar situation is unclear. The purpose of this study was to describe the impact of PAH on the lives of patients and their caregivers and to investigate the financial burdens imposed by PAH on the affected family. We also explored what type of PAH information was required by patients with PAH and their caregivers. Based on this survey, we hope to improve patients' and caregivers' experiences with PAH, to inform the scientific community, and to gather evidence to illustrate the need for a more comprehensive standard of care in Chinese population in the future.

2. Materials and methods

To explore participants' experiences of day-to-day living with PAH, a large-scale national survey investigated 3 key aspects affected by PAH (patients' lives; caregivers' lives; financial burden). This is a qualitative survey based on one-to-one interviews (see questionnaire in supplementary appendix, <http://links.lww.com/MD/B838>). This study was approved by the Ethics Committee of Beijing Hospital (2014BJYYEC-OS1-02) and informed consent was signed by all of the participants.

Data collection was conducted from September 2013 to January 2014 in 8 major cities in China. A sociodemographic and clinical data form was completed by 174 participants including 114 PAH patients and 60 caregivers. The mood and impact of PAH on the lives of the participants were reported by patients and caregivers.

The inclusion criteria of patients were: age ≥ 18 year-old; mPAP ≥ 25 mm Hg, and pulmonary artery wedge pressure (PAWP) < 15 mm Hg; and able to speak, read, and sign the informed consent form. The exclusion criteria were: terminal stage of any disease; pulmonary hypertension (PH) due to other reasons: left heart disease, hypoxic and lung diseases, or chronic thrombotic embolic disease; and known severe or enduring mental illness before PAH diagnosis.

Face-to-face interviews with PAH patients and caregivers were performed with questionnaire forms covering questions on financial conditions, physical and daily activities, emotional and social adaptations, and informational needs. The China PH Patient Group ISEEK Hope Center assisted with the survey to establish a good rapport. Data were presented as descriptive data or frequency, depending on the type of variable.

3. Results

The current investigation included 3 key sections: the impact of PAH on patients' lives, caregivers' lives, and the financial burden. According to clinical classification of PAH, there are 25 IPAH patients (22%), 15 CTD-associated PAH patients (13%), 69 CHD-associated PAH patients (61%), and 5 other kinds of PAH patients (4%) in this study.

3.1. Impact of PAH on patients

The majority of patients ($n = 114$; 80.9%) were women (78.7% were aged 20–40 years; mean age, 32.9 years). The current WHO functional class (FC) of the participants was predominantly FC II to FC III, 47% of patients were FC II, and 47% were FC III, 6% were FC I, none was FC IV. The main PAH etiology of patients was congenital heart diseases associated PAH [69 (61%)], followed by idiopathic PAH 25 (22%), connective tissue diseases associated PAH 15 (13%). The respondents' demographic characteristics are summarized in Table 1.

Table 1
Demographic characteristics of the respondents.

	Patients	Caregivers*
Subjects, n	114	60
Mean age, y	32.9	41.8
Females, %	80.9%	40.4%
PAH—etiology, n (%)		
IPAH	25 (22%)	
CTD-PAH	15 (13%)	
CHD-PAH	69 (61%)	
Others	5 (4%)	
WHO functional class, %		
I	7 (6.0%)	1 (2.4%)
II	54 (47.0%)	25 (41.5%)
III	53 (47.0%)	31 (51.2%)
IV	0 (0.0%)	3 (4.9%)

PAH=pulmonary arterial hypertension, IPAH=idiopathic pulmonary arterial hypertension, CTD=connective tissue diseases, CHD=congenital heart diseases, WHO=World Health Organization.

* Caregives were not coming from the same family as patients in our survey.

Table 2

Impacts on daily life of patients and caregivers.

	Impacts (patients/caregivers, %)
Patients (n=114)	
Sport activity/doing exercise	97.5%
Traveling/going on holiday	93.3%
Climbing a flight of stairs	89.4%
Going on errands, for example, shopping for food	88.0%
Dealing with domestic work/household chores	85.5%
Caregivers (n=60)	
I am more involved in household chores/go on errands	86.8%
I am more organized/take on planning of his or her daily life/involved in tasks my relative used to manage	86.5%
I have needed to make changes to my daily life	85.5%
I schedule our family life around her/his needs	84.9%
I feel exhausted more often (due to extra responsibilities)	84.6%

3.2. Significant influence of performance activities on patients

In patients with PAH, exercise capacity and WHO-FC were significantly associated with QOL. The questionnaire had a scale to the responses. For each aspect the participants had 5 choices: I am not affected in this; occasionally affected; sometimes I am affected; I am often affected in this aspect; It had great impact on me. The first response and the second response were considered as no impact in this aspect. This survey revealed the impact on physical activities; patients reported their physical activities such as sports (97.5%), travelling/vacations (93.3%) and climbing a flight of stairs (89.4%) were influenced. Activities of daily living such as showering or dressing were impacted in 66.1% of patients. Moreover, issues including errands (e.g., grocery shopping) and household chores were affected in 88.0% and 85.5% of patients, respectively (Table 2).

3.3. Employment/work

About 81% of PAH patients acknowledged impacts on working abilities postdiagnosis or working conditions (Fig. 1).

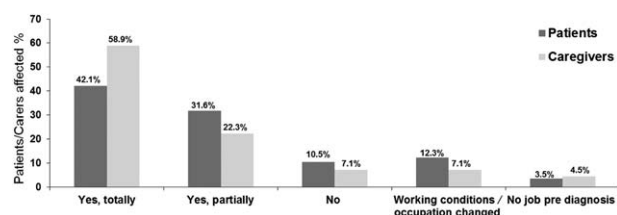


Figure 1. Impact of PAH on work and employment for patients and caregivers: more than a half of those participants had their work conditions affected. Special attention should be paid to the fact that more impacts were reported by caregivers. This may be resulted from the more responsibilities they take after their relatives get ill. PAH=pulmonary arterial hypertension.

Table 3

Frequency of emotions in the last months (patients, %).

	Impacts (patients, %)
Patients (n=114)	
Frustrated/restless/stressed	92.7%
Low self-esteem/confidence	89.9%
Lack of concentration/difficulty with remembering things/talking/thinking more slowly than usual	89.4%
Loss of libido/interest in sex	84.2%
Fearful/frightened at any time	82.0%

3.4. Feelings of isolation

For the PAH patients, 80.4% reported that their friends, family and colleagues do not understand PAH. Daily emotional impacts were significant. Figure 2 summarized these impacts. The most frequently reported impact was frustration, restlessness, or stress, with 92.7% of patients reporting these emotional troubles, followed by low self-esteem (89.9%), a lack of concentration or difficulty remembering things, and talking/thinking more slowly than usual (89.4%; Table 3). The majority of the participants (96%) found it difficult to express themselves effectively.

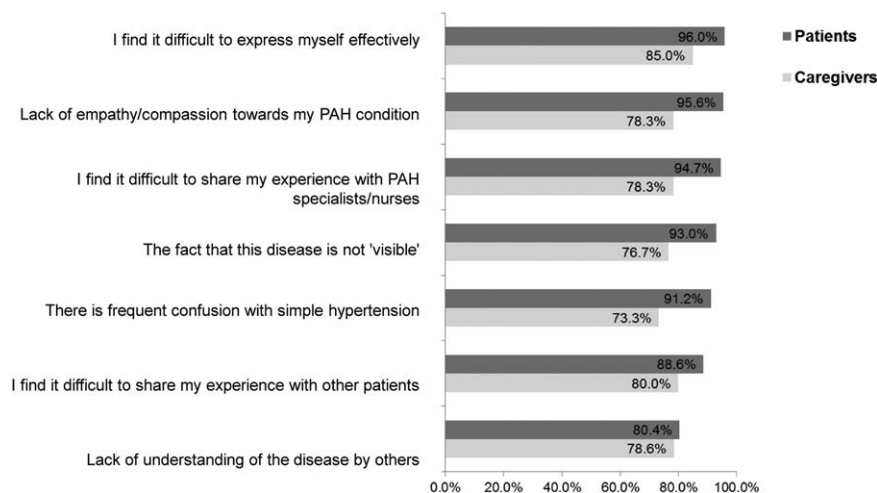


Figure 2. Causes for feelings of isolation as a result of PAH: social isolation was common among pulmonary hypertension patients and their caregivers. Data on the causes for feelings of isolation was presented in this table in a comparable pattern. PAH may influence interpersonal relation from various ways. PAH=pulmonary arterial hypertension.

Table 4**Frequency of emotions in the last months (caregivers, %).**

Impacts (caregivers)	(%)
I feel stressed caring for my relative and trying to meet other responsibilities for my family or work	87.7%
I feel that my relative asks for more help than he or she needs/I feel my relative is over dependent on me	76.8%
I feel that because of the time I spend with my relative, I do not have enough time for myself	76.8%
I am afraid about what the future holds for my relative	96.4%
I feel my health has suffered because I am caring for my relative	58.9%
I think that I should be doing more for my relative/I feel guilty that I should do more for my relative/I feel that I could do a better job in caring for my relative	67.9%
I feel that I will be unable to take care of my relative much longer	40.0%
I wish I could just leave the care of my relative to someone else/I feel I have no choice but to look after my relative	44.5%
I feel angry/strained when I am around my relative	45.6%
I feel that I have lost control of my life since my relative's illness	66.7%
I feel that I do not have as much privacy as I would like because of my relative	57.7%
I feel uncertain about what to do for my relative	63.5%
I feel that my relative adversely affects my relationship with other family members or friends/I feel caring for my relative gives me less time to spend with my children or grandchildren (if any)	63.8%

3.5. Impact of PAH on caregivers

About 40.4% of the caregivers were female (average age, 41.8 years). The caregivers were mainly family members of patients, but the patients and caregivers in this survey were not coming from the same family.

Most caregivers thought the impact on their daily lives was severe, including household chores or errands (86.8%), leading to the following statement: "I am more organized/take on planning of his or her daily life/involved in tasks that my relative used to manage." (Table 2). About 74% of PAH caregivers acknowledged impacts on working abilities postdiagnosis, with 31.6% indicating partially affected and 42.1% indicating "yes, totally affected" (Fig. 1).

3.6. Significant impact on daily emotions

Moreover, 85.0% of caregivers found it difficult to express themselves effectively, while 81.7% of caregivers reported a lack of understanding of PAH from the patient and their social group (Fig. 2).

During the interview, the most frequent concern from caregivers was what the future holds for their relatives

(96.4%) as common thought was that PAH patients have a dim future. Meanwhile, 87.7% of caregivers felt stressed caring for their relatives and trying to meet other family or work responsibilities. However, not all caregivers demonstrated enough patience or empathy for the patients. Most caregivers felt their relatives asked for more help than they need or were overly dependent on them (76.8%). The similar proportion felt that because of the time they spent with their relatives, the caregivers did not have enough time for themselves. However, some caregivers got the different feeling, saying "I think I should be doing more for my relative" (67.9%). More than half felt their health suffered because of caring for their relative (58.9%). Unfortunately, negative emotions were not rare (Table 4).

3.7. Informational needs

The following information was requested by >95% of caregivers and patients: information on PAH specialists and doctors for caregivers (98.2%) and for patients (96.5%). Most patients would like testimonials and patient stories (98.2%) (Fig. 3).



Figure 3. PAH information required by patients and caregivers: information required by patients and their caregivers was similar. Most information needed was related to the patients, directly or indirectly. PAH=pulmonary arterial hypertension.

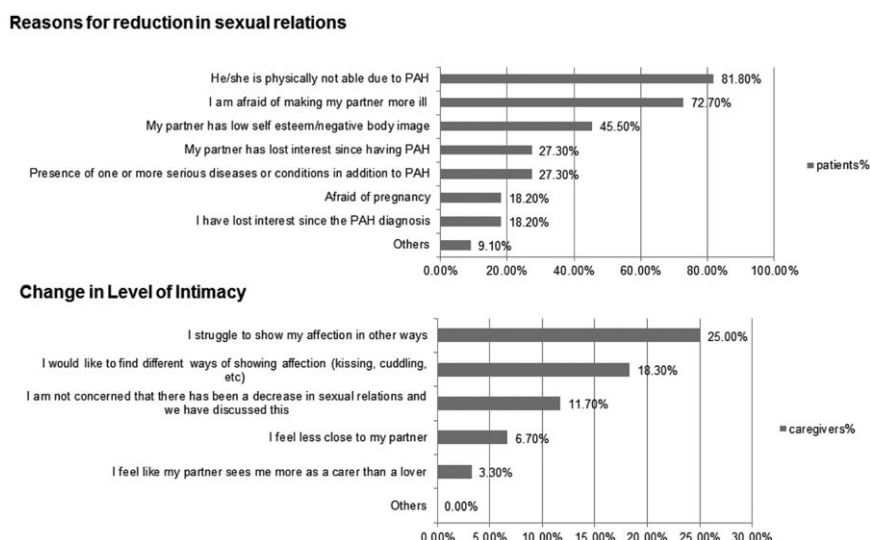


Figure 4. Impacts on sexual relations post diagnosis: data presented in the figure showed reasons for sexual impacts and change in level of intimacy between spouses (mainly from the angle of the caregivers).

Disease status including symptoms and prognosis was a common concern (98.2%, caregivers; 95.6%, patients). Caregivers expressed the need for more information on treatment options (98.1%) and administrative consequences of the disease and follow-up appointments including schedules and purposes (96.4%), which were closely related to their relatives' status.

In addition, PAH caregivers (98.2%) and patients (96.5%) would like patient organization contacts to obtain support (Fig. 3).

3.8. Impacts on relationships postdiagnosis

Many caregivers (84.2%) reported a reduction in intimacy and decreased sexual relations since their spouse became ill that declined further as PAH progressed. This investigation paid more attention to the impact on caregivers than that of previous studies, to our knowledge. Questions related to the impact on sexual relationships were investigated only among caregivers. Thirty percent of caregivers acknowledged the impact on their sex lives and the reasons for the reduction in sexual relations and change in level of intimacy were as follows (Fig. 4).

3.9. Financial burden

Patients from low-income families paid the most attention to or were frustrated by the impact of PAH on their finances. PAH imposed a heavy financial burden on families with PAH patients. The working ability of caregivers and patients was influenced. Naturally, the loss of the ability to work because of PAH had a significant influence on their household income.

This study revealed that 71% of patients' families earn less than 5000yuan/mo, while treatments cost them 3990yuan/mo on average. Our investigation found that 38% of patients paid over 5000yuan/mo for treatments. Because of the financial burden, over 50% of patients did not use any kind of PAH-specific therapies (Fig. 5).

During the interviews, we conducted an evaluation to assess the level of financial impact and found that it was more than we expected. The evaluation score ranged from 0 to 10 (0, no impact; 10, extreme impact), and 65% of the patients and 66.7% of the caregivers had a financial burden score of 10.

4. Discussion

PAH affects all aspects of patient life including daily activities, work, emotions, interpersonal relationships, etc.^[10] This research for the first time studied the impact of PAH on Chinese patients and their caregivers. In our survey, once diagnosed with PAH, most patients indicated that the most impacted aspect was their work, with diminished work abilities, which directly increased financial burdens. This study also showed that treatment expenses imposed a massive financial burden on families, while patients' physical capabilities were seriously impaired.

More than 90% patients mentioned difficulties in daily physical activities. The European survey reported that 56% of the patients indicated that PAH had a very significant impact on their daily lives.^[2] Almost all of PAH caregivers and patients from our survey would like to get information on patient organization contacts. The patients in Guillevin's study look toward patient organization for information support and emotional needs.^[2] This might indicate that there were not enough patient organizations in China or if there were, our patients had not found the access to contact them.

The vague and nonspecific symptoms of PAH including fatigue, shortness of breath, palpitations, lower limb oedema and syncope combined with a time-consuming diagnosis could result in emotional problems. All the above symptoms cause physical disability.^[11] Previous studies suggested diminished physical health and health-related quality of life (HRQOL) and a high prevalence of depression and anxiety in PAH patients.^[12-14] Emotional problems naturally arise during PAH progression. A lack of public understanding regarding PAH contributes to social isolation. The variable presence of PAH symptoms, particularly dyspnoea and fatigue, impact patients' life quality.^[8,15,16] In our investigation, we had studied a Chinese population with similar concerns and disease burden. The majority of patients had feelings of isolation and difficulties communicating with others. The fact that this disease is not "visible" contributes to a lack of understanding of the disease by others. Unfortunately, there is frequent confusion with simple hypertension. Their community showed less compassion toward PAH as a result of lacking knowledge on the disease. Thus, participants complained about

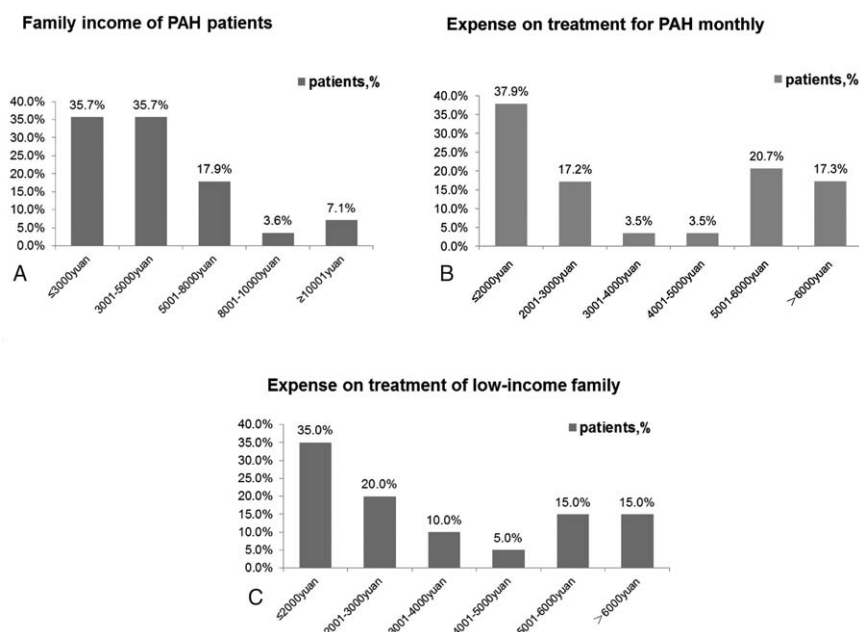


Figure 5. Financial burden: financial problems were especially serious in Chinese PH patients' family. Those 3 figures showed the financial condition in those families and the financial burden imposed by treatment for the disease. PH = pulmonary hypertension.

the lack of understanding of PAH in their community, including their spouse, children, or grandchildren. The feelings of isolation contributed to mental pressure. This effect initiated the involvement of caregivers and their families. The qualitative interviews by Guillevin et al^[2] revealed that more than half of their participants felt socially isolated resulting from a lack of understanding of PAH. However, their study also reported positive aspects, with most of caregivers believing that they contributed to the patient's QOL and nearly two-thirds felt that their care enabled them to have closer relationships as a couple or family that was rarely seen with our participants.^[2]

In this study, patients would like to get information regarding testimonials and patient stories. An international self-reported survey using market research methodologies was conducted in the United Kingdom,^[8] and a modified survey was also completed in the United States.^[17] American patients requested more information regarding the financial consequences of their disease, while European patients requested more information regarding specialists and doctors.^[8,17] Chinese patients were more likely to talk about the impacts of PAH on their lives with their family and friends, followed by patient organizations, PAH specialists, other PAH patients, etc. Similarly, more American patients found support from their friends, patient organizations, family doctor, nurse and spiritual or religious organizations. More Chinese patients regarded their family as the first place to talk about themselves, while less than a quarter of American patients reported that their family provided the most effective support and less than half of European patients thought their family provided the most effective support. Still, American patients tend to adopt a flexible attitude and maintain a positive self-image.

The relationship between patients and other family members changed subtly when the patients became ill. Both had to work harder expressing their thoughts and needs, leading to subsequent stress. Caring for patients and working exerted a heavy burden on their caregivers and the entire family. In the European

survey, caregivers thought caring for a PAH patient was physically exhausting, and 57% of caregivers indicated that PAH had a profound effect on day-to-day life, often resulting in exhaustion because of the additional tasks and responsibilities.^[2] In our study, a high proportion of the caregivers admitted that they were often exhausted because of caring for the patients.

Chinese caregivers most likely discussed their problems with family and friends and PAH specialists in the second place. American caregivers would likely seek physicians, support groups, or other patients; 69% of European caregivers were more satisfied with those close to them or family, as compared with American caregivers. Caregivers had great responsibilities such as errands, household chores, and financial problems. Chinese caregivers were more likely than European and American caregivers to report that their relative's PAH had a significant impact on their lives; meanwhile they reported more involvement in tasks that their relatives used to manage, such as household chores and errands, and had higher levels of exhaustion and organization.

Chinese caregivers were more likely to change their daily life or schedule their family life around the patients' needs. A lack of understanding and the invisibility of the disease are common reasons why caregivers feel isolated in the US and China, but the biggest problem in China was difficulty communicating with others. Caregivers are indispensable for patients' medical care and self-management. However, the level of social support caregivers obtain was low, and they lack information regarding help with caregiving.^[9] American caregivers reported they would like to receive regularly updated information on drugs used for PAH from healthcare professionals. Our study also found that Chinese caregivers expect to receive information regarding PAH treatment options or medications.^[9]

PAH imposed a heavy financial burden on families with PAH patients. Treatment for PAH, particularly drug therapy that seriously impacted their family finances. The working ability of caregivers and patients was influenced and resulted in a

significant influence on their household income. If national health insurance or social security system could offer support, their stress would be alleviated, and they could benefit from long-term therapy.

The necessity for treatment and tremendous financial burden causes dilemmas for many families. The participant's work, life, and emotions were impacted to varying degrees. Patients from low income families were concerned more about their finances. Among all families who participated in the interview, many families had low monthly income and what was worse, most of their income was used on treatments, which aggravated their poverty. The European survey conducted by Guillevin et al^[2] revealed that 85% of patients reported that their work or employment was affected by PAH. Both patients (73%) and caregivers (35%) reported a major impact on family finances.^[2]

5. Conclusions

This Chinese PAH patient and caregiver survey provided details on the profound impact of PAH. The financial burdens imposed by PAH and its treatment caused stress. It is of vital significance for healthcare professionals to provide more support and information for PAH families. This survey considered all aspects of life for PAH patients and their caregivers and could provide guidance for the future management of PAH.

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