BRITISH JOURNAL OF HOSPITAL MEDICINE

ARTICLE

A Qualitative Study on the Experiences of Patients with Pulmonary Hypertension Undergoing Polypharmacy

Yundan Wang[1], Run Huang[2], Yiyu Zhuang[2,*]

[1]School of Nursing, Zhejiang Chinese Medical University, Hangzhou, Zhejiang, China
[2]Department of Nursing, Sir Run Run Shaw Hospital, Zhejiang University School of Medicine, Hangzhou, Zhejiang, China
*Correspondence: zhuangyy@zju.Edu.cn (Yiyu Zhuang)

Abstract

Aims/Background Pulmonary hypertension (PH) is a severe progressive disease characterized by elevated blood pressure in the lungs. Medications are a critical form of treatment for patients with PH. This study aims to explore the experiences of patients with PH undergoing polypharmacy, thereby providing a more concrete foundation for formulating targeted intervention measures.

Methods A purposive sampling method was used to select 13 PH patients treated in a grade III hospital in Zhejiang Province from December 2023 to February 2024 as the research subjects. This study is a descriptive qualitative research design, where the patients were interviewed face-to-face in a semi-structured manner. The data were analyzed, summarized and extracted using the traditional content analysis method.

Results There were five themes and ten sub-themes surrounding the polypharmacy experiences of the PH patients: (1) Negative emotional experience of multidrug use, including lack of disease-related medication knowledge and insufficient ability to obtain medication information; (2) Complex physical testing of multiple drugs, including adverse reactions and complex dose titration; (3) Economic burden; (4) Coping difficulties, including insufficient drug safety, excessive reliance on medical personnel, and lack of opportunities for deep participation; (5) Desire for supports, including professional and social support, as well as those from family, colleagues and classmates.

Conclusion Disease, treatment, psychological factors, and social customs affect PH patients' drug use post-diagnosis, with varying experiences and degrees. Healthcare providers must offer tailored care and practical strategies for managing multiple drug use, considering patients' unique experiences and needs.

Key words: pulmonary hypertension; polypharmacy; experience; qualitative study

Submitted: 5 July 2024 Revised: 12 August 2024 Accepted: 18 August 2024

Introduction

Pulmonary hypertension (PH) refers to the clinical and pathophysiological syndrome caused by a variety of heterogeneous diseases (etiologies) and different pathogenesis leading to structural or functional changes in the pulmonary vasculature, resulting in increased pulmonary vascular resistance and pulmonary arterial pressure, which then leads to right heart failure or even death. About 1% of the global population suffers from PH, and the incidence can be as high as 10% in people aged >65 years (Galiè et al, 2019; Hoeper et al, 2016). In the era of traditional therapy without targeted drugs, patients with PH had a poor prognosis, with a median survival of only 2.8 years, and the 1-, 3- and 5-year survival rates are 68%,

How to cite this article:
Wang Y, Huang R, Zhuang Y. A Qualitative Study on the Experiences of Patients with Pulmonary Hypertension Undergoing Polypharmacy. Br J Hosp Med. 2024. https://doi.org/10.12968/hmed.2024.0392

Copyright: © 2024 The Author(s).

48% and 34%, respectively (D'Alonzo et al, 1991). With the advent of targeted drug therapy, the prognosis of PH has seen significant improvement. The U.S. REVEAL Registry study showed that since November 2001, the 1-, 3-, 5- and 7-year Kaplan-Meier survival rates of PH patients have shown an improvement to 85%, 68%, 57% and 49%, respectively, and the 1- and 3-year survival rates in China have improved to 92.1% and 75.1%, respectively, consistent with findings reported in developed countries (Zhang et al, 2011). Such improvement verifies that the current form of drug therapy, especially targeted combination drug therapy, is the best treatment option for mitigating symptoms and delaying the progression of PH (Mandras et al, 2021).

While the existing medications have been shown to enhance function measured by the 6-minute walking distance (6MWD) and delay clinical deterioration, they also have significant side effects that may negatively impact patients' quality of life (QoL) (Wilson et al, 2022). In addition, patients with PH need to use one or more targeted drugs, such as prostacyclin and its analogues, phosphodiesterase-5 inhibitors, and endothelin receptor antagonists, in addition to routine oxygen inhalation, anticoagulation, cardiac support, diuretic and other therapeutic measures, to improve the survival rate and improve clinical symptoms (Ruopp and Cockrill, 2022). This reflects the actual reality that multiple drug use, or polypharmacy, in these patients is inevitable.

World Health Organization (WHO) (World Health Organization, 2019) defines polypharmacy as taking five or more medicines at the same time every day, including over-the-counter medicines, prescription medicines, Chinese herbal medicines and health supplements. However, drug safety and compliance among PH patients are affected by the long treatment course, combination of drugs, variety of drugs, high cost, adverse drug reactions, and high requirements for drug titration in PH patients. Some patients have poor tolerance to adverse drug reactions, which even affect the quality of life. Studies have reported that 85% of patients using treprostinil injection experience painful adverse reactions, including headache, diarrhea, nausea, flushing, muscle pain, joint pain and jaw pain, which worsen their QoL and affect their compliance with completing the medication treatment (Christiansen et al, 2020; Wilson et al, 2022). However, in centers with high-volume PH patients, the vast majority of PH patients received targeted drug therapy, 57.2% received 2 to 3 combination therapy before death, and 70% received parenteral prostacycline therapy (Christiansen et al, 2020), indicating the crucial therapeutic role of drug therapy for PH patients.

At present, relevant studies on medication management for PH patients are limited, mainly focusing on the characteristics of drug types, mechanisms of action, and adverse reactions, as well as exploring new drug targets and pathways. Nursing studies domestically and abroad mainly focus on nursing intervention, and there is a lack of studies on the illness experience of PH patients (Levine, 2021; Humbert and Lau, 2021; Olsson et al, 2023). Therefore, the current research on medication management for PH patients still needs to be further expanded. In particular, understanding the medication experience of PH patients is key to providing targeted medication guidance according to the drug use status of patients, which is

determined by the adverse reactions caused by drugs, timely checking on medication compliance, and feedback to patients, so as to improve patients' compliance with drugs (Levine, 2021). Therefore, this study intends to investigate the medication experience of PH patients and delve into their perceptions of drug treatment, so as to provide a reference for the assessment of the drug use needs of patients and the formulation of targeted intervention measures.

Methods

Research Subjects

An objective sampling method was used to select PH patients who were admitted to the Department of Respiratory and Critical Care Medicine in a Grade III Class A general hospital in Zhejiang Province from December 2023 to February 2024 as the study subjects, and PH patients undergoing polypharmacy were selected. More representative and diverse data were obtained by interviewing patients with different genders, ages, education levels and disease courses. In order to avoid overrepresentation, additional sampling was conducted, the data of the interviewees became repetitive, and no new topics emerged as the standard for data analysis. The collected data were analyzed and quality control was carried out. Finally, a total of 13 patients were included as study subjects (numbered P1–P13). These subjects met the following criteria: (1) age $\geq$18 years old; (2) diagnosed with pulmonary hypertension; and (3) having taken at least 5 drugs for at least 3 months. Exclusion criteria for this study were as follows: (1) patients with critical condition; and (2) patients with communication impediment. The sample size was determined according to the principle of data saturation (Sim et al, 2018). The sample size was considered to have reached saturation when there were no new topics arose during the interviews.

Below is the WHO classification of pulmonary hypertension (Simonneau et al, 2013):

(1) First category: Pulmonary arterial hypertension (PAH);

(2) Second category: Left heart disease caused by PH;

(3) Third category: Pulmonary diseases and/or hypoxia caused by PH;

(4) Fourth category: Chronic thromboembolic pulmonary hypertension (CTEPH) and/or PH caused by other pulmonary artery obstructive diseases;

(5) Fifth category: Unknown and/or multifactorial PH.

A total of 13 PH patients were interviewed in this study. There were 5 males and 8 females, aged 18–72 years. According to the WHO classification of PH, there were 2 cases in the first category, 5 cases in the second category, 2 cases in the third category, 4 cases in the fourth category, and 0 cases in the fifth category. The demographic and clinical data of these respondents, numbered P1–P13 patients, were shown in Table 1.

Table 1. Demographic and clinical data of pulmonary hypertension patients (*n* = 13).

Number	Gender	Age (years)	Marital status	Educational level	Occupation	WHO classification	Cardiac function (NYHA grading)	Course of disease (years)	Number of drugs	Types of social insurance
P1	Male	53	Married	Senior high school	Freelancer	Second category	Grade III	5	10	Provincial card
P2	Male	26	Unmarried	Junior college	Others	Fourth category	Grade III	1	5	Provincial card
P3	Female	66	Married	Illiteracy	Peasantry	Fourth category	Grade III	5.5	9	Provincial card
P4	Female	70	Married	Secondary school	Retirement	First category	Grade III	2.5	6	Provincial card
P5	Female	18	Unmarried	Senior high school	Student	Second category	Grade II	9	5	Provincial card + Commercial insurance
P6	Female	44	Unmarried	Senior high school	Unemployed	Second category	Grade III	1.5	6	Provincial card
P7	Female	56	Divorced	Junior high school	Housewife	Third category	Grade III	3	8	Municipal medical insurance
P8	Female	45	Divorced	Grade school	Non-permanent occupation	Third category	Grade III	0.5	7	Self-paying (Commercial insurance)
P9	Male	53	Married	Junior high school	Other	Fourth category	Grade III	15	9	Rural insurance in other areas
P10	Male	69	Married	Grade school	Peasantry	Fourth category	Grade III	8	8	Provincial card
P11	Male	58	Married	Junior high school	Private business owner	First category	Grade II	3.5	5	Provincial card
P12	Female	72	Married	Grade school	Retirement	Second category	Grade III	30	11	Municipal medical insurance
P13	Female	55	Married	Junior high school	Peasantry	Second category	Grade III	23	6	Provincial card

Theoretical Basis

Research Design

The current study adopted the descriptive qualitative research design, based on the format of natural questioning, with the aim of providing an overall summary of the individual after experiencing a specific event (Lambert and Lambert, 2012). This method was selected to address the research problem of this study, which was framed by the presumption that reality is subjective, constructed, interpretable, and can change in different contexts.

Interview Outline

According to the purpose of the study, an interview outline was formulated after the literature review (Milne and Oberle, 2005; Yang et al, 2023) and discussion within the research group. Two patients with PH undergoing polypharmacy were selected for pre-interview. Through in-depth analysis of the pre-interview results, relevant literature was retrieved, followed by outline revision by experts, and further discussion and adjustment of the outline, until the interview outline was finalized. The ultimate interview outline is shown in the following:

(1) What are your symptoms and feelings during the whole illness process?

(2) Please talk about your experience in the process of polypharmacy. What is your understanding of the medications prescribed? (i.e., what are they for, what do they do, how important are they to you, do you know about these drugs, have you done any web searches about them?)

(3) What are your beliefs, feelings and experiences about adhering to multidrug therapy?

(4) How do you get information and support for your medication routine?

(5) Please talk about the difficulty you face in the continuous use of multiple medications and the factors that affect medication compliance.

(6) Please talk about your knowledge and practice in self-management of multidrug use.

(7) In your opinion, what measures can be taken to better meet your needs?

Data Collection

Prior to the interview, researchers were trained in relevant qualitative research knowledge and interview methods and forms. An interview outline was given to each of the PH patients undergoing polypharmacy as a guide to avoid affecting the integrity and accuracy of data collection. Before the formal interview, the interviewees were briefed on the research purpose and procedures. A semi-structured interview with each interviewee was conducted at the agreed time and place (single room), with the whole interview process being recorded. During the interview, we paid close attention to the interviewees' expressions, movements and intonation. The interview duration was controlled to within 30 to 45 minutes, but flexibility in this regard can be exercised for special circumstances. After each interview, the researcher transcribed the recording into text within 24 hours, and the transcribed data were checked by two people for data analysis. Any doubts concerning the data between the two researchers were investigated, and the interviewees were con-

tacted again to confirm whether the research results were consistent with their real experience and feelings, so as to improve the credibility of the results.

Data Analysis

In this study, the seven-step Colaizzi's method of data analysis was used to analyze the interview data. Three researchers who participated in the qualitative research worked together in jointly reading and analyzing the interview data sentence by sentence, extracting meaningful statements from the research subjects, and performing repeated comparisons and screening until a concise theme was formed. Briefly, the steps involved are as follows: (1) Review the interview material carefully; (2) Extract significant statements; (3) Encode recurring, meaningful ideas; (4) Encode meaningful ideas into thematic prototypes; (5) Write a detailed, original account of the subject; (6) Identify similar thematic concepts; and (7) Return to the interviewee for verification. Through the in-depth analysis of the data, the real medication experiences of PH patients were extracted.

Quality Control

In this study, we selected a sample of respondents that were well-representative of different characteristics. In order to avoid the Hawthorne effect, the interviews were conducted in a quiet and uninterrupted environment. During the interview, the principle of fairness and justice was adhered to, and communication skills were used to guide the interviewees to talk about their feelings as much as possible. The researcher pool method, in which the researcher invites another colleague to participate in the analysis of the same data and compares the results to improve the credibility of the results, was utilized too. In the process of data analysis, we employed the consensus method, through which, the researcher listens to, reads and analyzes the recorded data repeatedly.

Results

Theme 1: Excessive Negative Emotional Experience with Multidrug Use

There were significant differences in negative emotional experiences in PH patients undergoing polypharmacy. In the process of medication use, the lack of disease-related medication knowledge and the insufficient ability to obtain medication information lead to negative emotions such as fear and anxiety.

In-Hospital Diagnosis Stage: From Unfamiliar Shock to Fear and Worry

Due to the rarity of PH, the patients feel unfamiliar and shocked about the disease and medications upon diagnosis, and gradually transition to fear and worry about multiple medications prescribed.

Most PH patients often experience some twists and turns in the diagnosis, "I went to a lot of hospitals and do not know what the disease is, the doctor of the county hospital said that he is unable to find the reason." (P7). "At that time, I was in shock and I really didn't know what was going on, I thought it was a name I saw in the small hospital. This year, they said that they did not dare to continue to treat me." (P10). "Well, I didn't know about the disease at that time. The only thing I

remember is that they said the medicine for this disease is going to cost me a lot of money because they are very expensive. I just feel like it's too much, so... I have to take so many drugs, but also take two or three targeted drugs, will it be bad for the liver and kidney?" (P7).

In-Hospital Treatment Stage: Becoming Concerned, Actively Seeking Knowledge, and Over Worrying Due to Lack of Knowledge

After being diagnosed with PH, most of the patients had the tendency to fall for unverified information from the outside world, making their pathological condition more severe. "The content I read on the Internet is quite consistent with my situation, and I am a little afraid." (P5). "The doctor said that the disease like mine could not be treated in their hospital, so I felt in my heart that it was probably difficult to get better." (P4). "The doctor said that to treat this disease, I need to take several kinds of drugs for a long time, and I was particularly afraid when I checked those drugs on the Internet. I feel that this disease makes me different from others. Will it bring inconvenience to my life in future?" (P5). Patients with PH are under great pressure once finding out they need to take multidrug therapy. "I checked the drug instructions online; I'm shocked to learn that these drugs have a variety of adverse reactions." (P12). Some patients obtain unscientific information from fellow patients and become more concerned about the new drug use. "A patient said that the needle with treprostinil will cause inflammation once injected, and she advised me that I better not use it... They said it hurt a lot for a few days, and I was so scared. I used to use peripheral injections so I was worried about inflammation, so I didn't really want to be injected with this medicine. Not many people get this injection, right? I'm so worried..." (P13). "I have been losing a lot of hair recently, but I don't know which medicine I am taking is responsible for the hair fall." (P6).

Early Stage of Discharge: Feeling of Pressure and Loss of Assistance

There are many types of medications given to the PH patients; therefore, they are vulnerable to feelings of pressure and helplessness regarding medication management in the early stage of discharge. Medications for PH patients include oral medications, subcutaneous pumps, subcutaneous anticoagulant injections, and intravenous medications. Managing the side effects of prostaglandins requires considerable skill. Oral medications are more convenient for patients than subcutaneous and intravenous medications, so doctors tend to modify the mediation plans by switching non-oral medications to oral medications with the objective to simplify medications for patients before discharge. If full oral administration is not possible, intravenous or subcutaneous injection should be continued after discharge. Many patients feel stressed before discharge: "I have to take at least 9 pills a day, in order to treat COPD, in order to treat the heart and pulmonary hypertension... There is only an old man at home, I do not know how to deal with this medicine, and they will not handle it in our local hospital." (P12). The existence of comorbidity has brought challenges to the accuracy and safety of patients taking medicine: "Now I have really poor memory and many physical problems, taking blood pressure drugs, inhalation drugs, stomach drugs... I was eating and I left something behind, alas,

how to do?" (P12). Female patients tend to reject the pump: "I hope to take oral medicine, or medicines convenient to me. With that medicine pump, I look ugly if I wear a skirt out in the summer." (P13).

Post-Discharge Adjustment Period: Guilt and Positive Response

Patients have positive and negative emotions during the adaptation period after discharge. The pressure of patients sometimes stems from the meticulous care of family members: "Every day after discharge I feel out of breath, family members are particularly good to me, I really am under great pressure. My parents always asked me to go to bed early, and I responded with just one word because I felt very irritable and impatient. Later, I regretted not knowing how heavy those words are." (P8).

Male patients have a high degree of acceptance of multiple drugs, and they are even willing to accept using a pump: "I thought this disease was hopeless, and now I am lucky to be alive. It's OK, this pump is very small, I usually put it in my pocket, so others would not see it. Oh, this medicine has to be used now." (P9).

Theme 2: Complex Physical Testing of Drugs

The majority of patients suffer from a severe symptom burden, including significant perception of somatic symptoms and impaired QoL. People with PH often experience difficulty breathing, phlegm in the throat, and low oxygen saturation.

"My whole body is uncomfortable, and I am also sensitive to light and do not want to go out." "I now do not dare to turn on the air conditioning in the winter time, as I am afraid of catching a cold. I do not dare to contact people, as I am afraid of spreading the virus." "I have a bad appetite and no energy. It felt like everyone had better leave me alone, being in a bad mood, being upset." (P8).

Perceived Benefits

Drugs are effective in modulating perceptual aspects. "I was so short of breath that I couldn't walk more than a few steps. And I am much more afraid of the cold, and do not dare to touch cold water. I am so angry that I cannot walk a few steps. It wouldn't have been as bad if I'd known I was taking the pills. I was reluctant to take drugs for polymyositis and pulmonary hypertension due to the fear of side effects." (P8).

Adverse Drug Reactions

The adverse reactions caused by drug treatment were not timely reported to the medical staff by the patient. "When just using the medicine, I would feel a little dizzy and headache, and the whole body is uncomfortable, and it will be better after a long time." (P1). "The arm here. This is where it hurts. Nowhere else." (P3). "When the dosage was adjusted up at the beginning, the pain caused by the needle was terrible, and I could not sleep at night, and I dared not turn over, and there's no way to cure it." (P9).

"Now when the medicine is added, I feel drowsy all day long, headache, dizziness and fear of light, and bone pain. That's why I felt afraid when the doctor asked me to increase the dose." (frowns) "But I feel much better now." (P8).

Tolerance for More Uncertainty of Drug Dose Adjustment

Some PH medications need to be titrated gradually, and patients cannot take their own medication regularly. "If you eat according to the set amount, it is good; otherwise you will always bother the doctor." (P13). At the same time, the process of drug titration elicited a more profound reaction in the patients, and they endured greater discomfort and psychological pressure: "The Selexipag, at that time, caused me to suffer from diarrhea every day, and my face turned very red. It was so uncomfortable that I persisted for almost a month, and then when the doctor added the medicine, I began to worry and be afraid. I wanted to stop taking it because of the side effects." (P5).

Theme 3: Heavy Economic Burden of Drug Treatment

Because PH is difficult to cure and recurrent, patients need long-term medication to control the condition, and the economic pressure generated by the exorbitant medication costs is a major factor driving incompliance: "I spent nearly 50,000 yuan (Exchange rate of US dollar against RMB at 7.0531) in hospital this year, as well as the usual asthma medicine, which is now nearly 3000 a month." (P7). Due to the adjustment of the medical insurance policy, the burden on patients has been reduced to a certain extent: "Although several drugs of this pulmonary hypertension are covered by the medical insurance, which are slightly reimbursable, most of them needed to be self-funded, and it would be good if the medical insurance could cover more."

Patients often bear a huge psychological burden due to economic expenditure: "My family supports me to take medical treatment, but now my grandson has not yet grown up, and my son? The family is not said to be very rich, so we also need to help take care of him. So there's still some reluctance. A burden to my family, alas..." (P4). Some patients also suffer from a certain inferiority complex. "The biggest difficulty is the economic aspect; I count on my family for all the expenses, my parents are really not wealthy, and the economic conditions at home are also not very good. If there are no symptoms, I will secretly eat two packets less every day, so that a box of the medicine can keep me sustained for a longer time." (P8). "If you are hospitalized, you will have to pay 3000 or 4000 yuan for expenses anyway, and medicine alone will cost about 1500 yuan a month. I pay for Treprostinil, which costs a thousand handfuls a month. In addition, I also need to take rivaroxaban, digoxin, diuretic drugs for heart, levofloxacin, and then aerosol drugs and many other drugs. Fortunately, I have an insurance plan, bought through my brother. I don't think I can afford it without medical insurance." (P8).

Theme 4: Difficulty Coping with Multidrug Use

Polypharmacy, to a certain extent, disrupted the patient's original rhythm of life: "Usually in school, because the teacher would start the class early and then finish the class late, the time to take medicine is very limited. I basically have no time to take medicine, or will miss a few times. There is no way this can be done regularly." (P5). "We are everyday medicine users but it is really inconvenient to take some of them. I can't take this medicine myself, it is inconvenient, and I have

to trouble my daughter to come and help me." (P3). "It is inconvenient to take a bath. You can cook. I won't touch the water here. Not when it comes to water. I'm just gonna grab a towel and wipe myself dry." (P3).

Many PH patients receiving polypharmacy, especially those discharged with pumps, have insufficient participation energy and limited participation strategies, and excessively rely on medical staff. The manifestations include insufficient medication safety, poor communication with medical staff, limited communication between caregivers, and a lack of cognitive and symptom management skills. "When I returned home, I found that the subcutaneous puncture site was oozing blood, I did not know who to contact, and I was afraid of being hospitalized again." (P13). "I was bitten by a dog yesterday, received an injection, and now take targeted drugs and rivaroxaban. I don't know if I can get a shot. If there is a reaction, it will be a problem." (P6). "The last prescription was 0.2, slowly changed to 0.6 over a few days, and I can't take my medicine... It is so difficult to break a pill into 1/4 pieces, so I resorted to biting it, and the amount is not accurate." (P6). "I am used to symptoms, but I do not know when they will get better." (P6). These patients' responses show a lack of self-medication management ability.

Theme 5: Desire for Supports

Desire for Family Support

Some patients yearn for more care from their families. Most patients reflected the effect of drug treatment is good, with treprostinil pump for severe PH especially showing apparent effect. But operating the pump is troublesome, necessitating assistance from others, causing many to not adhere to long-term medications: "This pump is fine, but adjusting the dose and changing the needle position is very troublesome. I need to rely on my daughter to help me when she comes back, but my daughter is not very good at it, even after learning the techniques shown in your video given to me a long time." (P9). "During my most uncomfortable period, my husband did not understand, even did not cook for me." (P3).

Desire to Gain Support from Colleagues/Classmates

Some patients get help from colleagues and classmates. "I have a bestie. I typically share happy things, no matter how big or small, with him. I would tell him about my sickness and the little misunderstanding with the classmates." (P5). "I worked as a kitchen helper in the school cafeteria, and I couldn't lift heavy things or climb the stairs, sometimes my little sisters would come to help me, and it was always embarrassing..."

Desire to Obtain Professional and Social Support

For some patients, visiting certain hospitals poses a challenge and medical treatment is inconvenient. Among the interviewees, one patient came from another province, and the rest of the patients from the province were not locals. All of them felt convinced and safe to be treated by the same medical team. "I work in the field. I travel to Hangzhou every month to review the prescription. This is really inconvenient, especially when work is busy, giving me so much time to rush back and

forth. But there is no other way, and I still believe in Director Ma." "The drugs I am using are special, and I cannot buy them in our local hospital and pharmacy. So, in order to get the medicine, I need to get up at 4 o'clock, when I am still very sleepy, to run over to other hospitals. I really hope the nearest hospital can start dispensing this kind of drugs." (P8). "The local hospital did not recognize this device. I went back to them with a problem, but they said they had never seen it nor did not know how to deal with it."

Among the interviewees, three patients were dissatisfied with going to the hospital for follow-up visits, mainly because of the longer waiting time for medical treatment, especially in delayed dispense of medicine, which is one of the driving factors of the non-compliance phenomenon. "I just want to take some medicine. Every time I come to the hospital, I have to wait for a long time, but my work is quite busy. Plus, the pills they gave can only last a few days. It is best if we can be given the medicines for 3–4 months." (P11).

For patients in the mild to moderate or remission period, adverse drug reactions may affect their physiological functions, work and life, influencing their medication compliance. "At that time, I had been taking this medicine for more than 20 days. The reaction was very big, very painful, and because of the pain, I could not sleep. Last year, I wanted to contact you, the dose was adjusted from 5.4 to 5.6. It's too much to bear, causing me to puke and poop. Seeing food makes me nauseous and throw up. I can't eat the food. I really can't stand it anymore. I called my daughter and said: 'Daughter, come back quickly, I can't bear it, please take me to the hospital.' WeChat was not available at that time. I was thinking about whether I should stop using these drugs." (P3). "I know you doctors and nurses are very busy, sometimes I hope to contact you, because it is best to communicate face to face." "Thanks to the online science courses, I know it is important to come for follow-up and review on time. Such education is very essential." (P7). "It would be nice to have health insurance paid out every three or four months." (P9). "For people coming from low-income households like me, sometimes the community would send volunteers to accompany me to see a doctor and get prescriptions, so I feel very grateful." (P13).

Discussion

Complex Experience and Needs of PH Patients Undergoing Polypharmacy

Improvements in PH care can extend the lives of patients, and the nature of their needs has changed accordingly. The patients have become more aware of the impact of the disease on their daily activities and QoL, and by focusing on the patient's perspective, more can be done to improve overall care and patient engagement. In this study, the PH patients receiving multidrug treatment reported a diverse range of physical and mental needs and complex experiences with polypharmacy.

The characteristics of psychological development, as the disease progresses, are in line with the timing theory. According to this theory, it is necessary to formulate corresponding countermeasures, through effective education and timely, high-quality information transmission and exchange about the role, significance and pre-

cautions of drugs. Patients are encouraged to participate in a multidisciplinary medication management system that includes healthcare professionals, caregivers, patient associations, and expert patient programs. First of all, during the diagnosis period in the hospital, we need to focus on the education of disease-related knowledge; during the hospital treatment period, we need to focus on the education of new targeted drugs; and prior to discharge, it is necessary to simplify drug plans, identify the main management personnel of non-oral drugs, and strengthen patients' skills in self-care, ensuring the correct usage of drugs after discharge.

In response to the physical testing of drug use, medical personnel must carry out early prevention, identification and intervention to avoid the double blow of serious side effects to patients, provide patients with the best possible care and support, improve their ability to cope with the disease, and help them effectively self-manage their disease. We should also develop a medication management pathway for PH patients on multidrug use, implement workshops for them to strengthen their skills and knowledge, and raise the hope of caregivers and family members for the patient's survival.

Improving Polypharmacy Experience of PH Patients through Various Ways

It is necessary to pay attention to the process and experience of multidrug use in PH patients in order to improve their drug management ability and disease coping ability, thereby enhancing their QoL. It is also important to improve the polypharmacy experience of PH patients and enhance their perception of the care given.

Strengthening Health Education on Drug Use for Patients and Correcting Their Misconceptions

The patients should be taught the knowledge of disease treatment and drug use, such as the mechanism of action, dosage and adverse reactions, and be informed of other obstacles that make adhering to the correct drug use impossible. The health education given by the medical staff is not only limited to the guidance on healthy lifestyle and diet, but also includes the education of multidrug knowledge, so as to improve patients' attention to drug treatment. Medical staff should use the lingua franca to explain the role of drugs, correct use and possible adverse reactions. They should also emphasize the necessity of adhering to the correct use of drugs, answer patients' questions, and correct their misperceptions. Nurses should offer guidance to patients on how to operate the subcutaneous pump, emphasizing the key aspects to help the patients and their families remember the skills and steps. Network resources should be used to build an information exchange platform for PH patients, so as to timely solve the physical and mental problems of patients in the process of medication treatment, disseminate disease knowledge to the patients, and induce a positive change in their behavior and attitude.

Improving the Medical Insurance System and Reducing the Financial Burden of Patients

Most of the patients interviewed have rural cooperative medical care or urban medical insurance, which does not cover the wide variety of drugs used to treat PH, as most of them are costly imported drugs. The high cost of these drugs has

become a burden for them, making it difficult for them to adhere to the medication treatment, further exacerbating medication compliance among these patients. It is worth noting that medication compliance in self-paying and low-income patients is even worse. In addition, although universal medical insurance is available in China, the uneven distribution of medical resources and limited access to medical resources particularly in rural areas, has led some PH patients to give up maintenance treatment once their condition improves. These patients only go to the doctor during a relapse or deterioration of the condition, which causes disease aggravation and increased financial burdens. Therefore, the health administration department should strengthen the reform of public hospitals, improve the medical insurance system, and increase medical subsidies for PH patients, while attending doctors should reasonably select drugs that are the most suitable for the patients, given their actual scope of conditions, with the secondary aim of lowering drug costs and patient burdens.

Establishing a Disease Management System

A disease management system involving full-time nurses for PH and an optimized treatment process for specialized diseases is warranted. Some of the interviewed patients indicated that there was a lack of reminders during medication treatment, leading to missing drug-taking time. Being swamped with work, forgetting and going out may also lead to untimely use of medication. Regularly reminding patients to return to the doctor is an important measure to prevent them from drug reduction and withdrawal, but at present, the self-management ability of PH patients remains low, and the lack of supervision and reminders from medical staff adds considerably to the limited self-management by patients themselves. Thus, it is necessary to establish a PH disease management system, which can maximize the advantages of having PH specialist nurses in the medical teams. In this system, a disease manager would intervene and follow-up a patient's treatment process, and offer education to the patients when required. PH disease managers need to formulate targeted health care plans for the patients, provide interventions to patients and their families, make them pay attention to the treatment of patients, and urge patients to follow the doctor's advice to take the medications on time and in the right dosage.

Although regular follow-up is the basic procedure used to monitor the condition and prevent disease recurrence in patients, this study found that the inconvenience of complying with follow-up appointments is one of the main driving factors leading to poor medication compliance in patients. Hence, PH disease managers and the healthcare team must keep in touch with patients to constantly remind them of the importance of regular visits. According to the survey, patients need to spend a long time on registration, treatment, examination, payment, medicine collection, etc. The average outpatient time is 1.5 hours, and the waiting time is much longer than the time taken for clinical diagnosis and treatment. Therefore, it is particularly important to optimize the treatment process for specialized diseases by placing a major focus on the patients, using information technology and systems as helpful tools for optimization. The implementation of an information-sharing system, the estab-

lishment of avenues for sharing patients' information files, the holding of special disease cards for medical treatment, and the optimization of appointment services can substantially shorten the processing time. The implementation of an information management network that entails sending diagnosis and treatment reminders and making appointments through the network, as well as providing pathways for making inquiries, sharing inspection results, placing medical orders, and sending electronic prescriptions can shorten the diagnosis and treatment time for PH patients, making the process of receiving medical treatment more convenient, and ensuring treatment continuity and accuracy.

Strengthening Psychological Counseling for Patients

Some patients expressed that the disease makes them feel embarrassed and ashamed, producing negative emotions such as anxiety and low self-esteem. They are reluctant to tell others that they suffer from chronic diseases, for fear of being labeled and questioned by others, which would have an impact on their work and personal life. The embarrassed patients often apply the wrong coping methods to conceal their conditions and dodge the questions, or change their medication frequency and dosage without consulting the physicians—a behavior that reduces their medication compliance. In this regard, medical staff should pay attention to the psychological problems of patients and emphasize the importance of having an optimistic attitude and a stable mood for the sake of disease control. They should also strengthen communication with patients, encourage family members to care for and support patients, alleviate patients' negative emotions, and enhance their confidence throughout the treatment process.

Limitations and Considerations of This Study

Several limitations of this study cannot be neglected. Firstly, a small sample consisting of only 13 patients with PH undergoing polypharmacy was recruited for this survey from a Grade III Class A hospital in Zhejiang Province. In the future, follow-up studies involving a larger sample will be conducted to verify these findings. The prime reason we did not include PH patients from other regions of China for this survey is that patients receiving treatments elsewhere may have different medication experiences.

Conclusion

In summary, through in-depth interviews with 13 interviewees, this study revealed the polypharmacy experience of PH patients, offering new insights that cannot be provided in quantitative studies. The phenomenological approach of qualitative research was adopted in this study to gain a more comprehensive understanding of the real multidrug experience of patients with PH, and to provide a reference for the future management of multidrug use in these patients. Medical staff should pay attention to the distinctive factors of each individual PH patient and formulate effective, personalized coping strategies in support of medication management, so as to improve their medication compliance, polypharmacy experience and QoL, while striving to achieve or maintain a low-risk state in these patients. In the future, we

can learn from foreign experience to deeply explore the inner needs and influencing factors of patients, in order to provide more comprehensive reference for medication management of patients with PH.

Key Points

- The negative emotional experience of multidrug use includes the lack of disease-related medication knowledge and insufficient ability to obtain medication information.
- Implementing the physical test for multiple drugs, such as analyzing adverse reactions and performing complex dose titration, is complex.
- The drug treatment for pulmonary hypertension is costly. Coping difficulties, including low drug safety, excessive reliance on medical personnel, and lack of opportunities for deep participation, are issues that need resolution.
- Patients with pulmonary hypertension also desire support, including professional and social support, as well as those from their family, colleagues and classmates.
- Medical staff should pay attention to individual factors of patients and formulate effective coping strategies for medication management support, so as to improve their compliance with multidrug use.

Availability of Data and Materials

The data used to support the findings of this study are available from the corresponding author upon request.

Author Contributions

YDW, YYZ and RH were responsible for the concept and study design, provided a critical review of the manuscript; YDW and RH were responsible for data collection, data analysis; YDW and RH were responsible for drafting the manuscript and all authors contributed to the critical revision of the manuscript for important intellectual content. All authors read and approved the final manuscript. All authors have participated sufficiently in the work and agreed to be accountable for all aspects of the work.

Ethics Approval and Consent to Participate

This study was approved by the Ethics Committee of Sir Run Run Shaw Hospital, Zhejiang University School of Medicine (Ethics approval number: Ethics 2024 Research No. 0366). All respondents participated in the study voluntarily and signed informed consent. The study was carried out in compliance with the Declaration of Helsinki.

Acknowledgement

Not applicable.

Funding

This study is supported by Zhejiang Medical and Health Science and Technology Project (2022PY06).

Conflict of Interest

The authors declare no conflict of interest.

References

Christiansen D, Porter S, Hurlburt L, Weiss A, Granton J, Wentlandt K. Pulmonary Arterial Hypertension: A Palliative Medicine Review of the Disease, Its Therapies, and Drug Interactions. Journal of Pain and Symptom Management. 2020; 59: 932–943. https://doi.org/10.1016/j.jpainsymman.2019.11.023

D'Alonzo GE, Barst RJ, Ayres SM, Bergofsky EH, Brundage BH, Detre KM, et al. Survival in patients with primary pulmonary hypertension. Results from a national prospective registry. Annals of Internal Medicine. 1991; 115: 343–349. https://doi.org/10.7326/0003-4819-115-5-343

Galiè N, McLaughlin VV, Rubin LJ, Simonneau G. An overview of the 6th World Symposium on Pulmonary Hypertension. The European Respiratory Journal. 2019; 53: 1802148. https://doi.org/10.1183/13993003.02148-2018

Hoeper MM, Humbert M, Souza R, Idrees M, Kawut SM, Sliwa-Hahnle K, et al. A global view of pulmonary hypertension. The Lancet. Respiratory Medicine. 2016; 4: 306–322. https://doi.org/10.1016/S2213-2600(15)00543-3

Humbert M, Lau EMT. Risk Stratification in Pulmonary Arterial Hypertension: Do Not Forget the Patient Perspective. American Journal of Respiratory and Critical Care Medicine. 2021; 203: 675–677. https://doi.org/10.1164/rccm.202012-4350ED

Lambert VA, Lambert CE. Qualitative descriptive research: An acceptable design. Pacific Rim International Journal of Nursing Research. 2012; 16: 255–256.

Levine DJ. Pulmonary arterial hypertension: updates in epidemiology and evaluation of patients. The American Journal of Managed Care. 2021; 27: S35–S41. https://doi.org/10.37765/ajmc.2021.88609

Mandras S, Kovacs G, Olschewski H, Broderick M, Nelsen A, Shen E, et al. Combination Therapy in Pulmonary Arterial Hypertension-Targeting the Nitric Oxide and Prostacyclin Pathways. Journal of Cardiovascular Pharmacology and Therapeutics. 2021; 26: 453–462. https://doi.org/10.1177/10742484211006531

Milne J, Oberle K. Enhancing rigor in qualitative description: a case study. Journal of Wound, Ostomy, and Continence Nursing. 2005; 32: 413–420. https://doi.org/10.1097/00152192-200511000-00014

Olsson KM, Corte TJ, Kamp JC, Montani D, Nathan SD, Neubert L, et al. Pulmonary hypertension associated with lung disease: new insights into pathomechanisms, diagnosis, and management. The Lancet. Respiratory Medicine. 2023; 11: 820–835. https://doi.org/10.1016/S2213-2600(23)00259-X

Ruopp NF, Cockrill BA. Diagnosis and Treatment of Pulmonary Arterial Hypertension: A Review. JAMA. 2022; 327: 1379–1391. https://doi.org/10.1001/jama.2022.4402

Sim J, Saunders B, Waterfield J, Kingstone T. Can sample size in qualitative research be determined a priori? International Journal of Social Research Methodology. 2018; 21: 619–634. https://doi.org/10.1080/13645579.2018.1454643

Simonneau G, Gatzoulis MA, Adatia I, Celermajer D, Denton C, Ghofrani A, et al. Updated clinical classification of pulmonary hypertension. Journal of the American College of Cardiology. 2013; 62: D34–D41. https://doi.org/10.1016/j.jacc.2013.10.029

Wilson M, Anguiano RH, Awdish RLA, Coons JC, Kimber A, Morrison M, et al. An expert panel Delphi consensus statement on the use of palliative care in the management of patients with pulmonary arterial hypertension. Pulmonary Circulation. 2022; 12: e12003. https://doi.org/10.1002/pul2.12003

World Health Organization. Medication safety in polypharmacy: technical report. 2019. Available at: https://www.who.int/publications/i/item/WHO-UHC-SDS-2019.11 (Accessed: 10 October 2022).

Yang Z, Sun L, Sun Y, Dong Y, Wang A. A Conceptual Model of Home-Based Cardiac Rehabilitation Exercise Adherence in Patients with Chronic Heart Failure: A Constructivist Grounded Theory Study. Patient Preference and Adherence. 2023; 17: 851–860. https://doi.org/10.2147/PPA.S404287

Zhang R, Dai LZ, Xie WP, Yu ZX, Wu BX, Pan L, et al. Survival of Chinese patients with pulmonary arterial hypertension in the modern treatment era. Chest. 2011; 140: 301–309. https://doi.org/10.1378/chest.10-2327