

ORIGINAL RESEARCH

Patient Perspectives and Side-Effects Experience on Chemotherapy of Non-Small Cell Lung Cancer: A Qualitative Study

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Purpose: This study aimed to explore patients' experiences of palliative chemotherapy for non-small cell lung cancer (NSCLC), how patients adapt to their new and challenging life after chemotherapy, their beliefs, and their quality of life.

Patients and Methods: The study used an exploratory descriptive qualitative approach that was designed to explore the experiences and side effects of NSCLC patients on chemotherapy in Pakistan. The study was designed to obtain a deeper understanding of 22 NSCLC patients' experiences, using a face-to-face approach and interviews were conducted. Patients who have completed chemotherapy agreed to participate in semi-structured interviews.

Results: The data were arranged into five themes: hospital facilities and environment, patient's beliefs in alternative treatments, presenting a positive/negative face, life is for living, and health insurance coverage. The major complaints related to bad experiences of chemotherapy-induced side effects, but these patients still managed to complete the full course of their respective chemotherapy. Additionally, the current study revealed the real experience of patients with NSCLC which had been less studied. The patient's experience was summarized into four themes and several subthemes.

Conclusion: This study aid healthcare providers when deciding on treatment options that will improve shared decision-making between clinicians and treatment outcomes.

Keywords: chemotherapy, NSCLC, qualitative research, semi-structured interview

Introduction

Lung cancer is the most prevalent cancer worldwide. Death rates continue to rise (1.6 million deaths/year) due to lifestyle and environmental factors, mainly cigarette smoking, pollution, and occupational carcinogens. Current trends in smoking are an alarming predictor of lung cancer incidence. Lung cancer's symptoms are cough and sputum, dyspnea, hoarseness of voice, chest pain, fatigue, weight loss, hemoptysis, and pneumonia. There are two main forms of lung cancer: non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). NSCLC is the most common type of lung cancer, accounting for 85% while 15% of the patients are SCLC. The NSCLC is further classified as adenocarcinoma, squamous cell carcinoma, and large cell. Treatment options for NSCLC patients depend upon disease stage and characteristics such as combination or sequence, including chemotherapy, targeted therapy, radiation, immunotherapy, and surgery. In Pakistan, approximately 8500 new cases are diagnosed in 2020. NSCLC treatment is stage-specific, and surgical resection is more suitable for patients with stages I or II. However, this approach to early-stage, NSCLC remains complex and unique to the patient. Nonsurgical patients should be considered for conventional or stereotactic radiotherapy. Chemotherapeutic regimens are helpful in metastatic cancers and also as neoadjuvant therapy to shrink

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the tumor size before surgery.^{6,7} These regimens show very promising results, but chemotherapy is the last resort in management. However, adverse effects of chemotherapeutic drugs may cause numerous immediate side-effects to patients (eg, hypotension), short-term (gastrointestinal disturbances), and long-term (renal toxicity, sexual dysfunction). It would also influence food intake to minimize gastrointestinal symptoms, which may lead to nutrition deficiency.8 Due to the known various side effects brought by chemotherapy, compliance with treatment is important to manage a particular disease, but due to multiple adverse effects, patients might not adhere to the treatment. 9,10

Despite the known various side-effects of chemotherapy, NSCLC patients may have concerns and worries before receiving chemotherapy. Although patient preferences have been systematically examined in some cancer types, there is still limited knowledge about how patients with non-small cell lung cancer (NSCLC) value the potential benefits and risks of chemotherapy. 11 Previous studies have focused on patient preferences for second-line chemotherapy and the utility of alternative therapies in NSCLC patients, but more research is needed to understand how NSCLC patients view chemotherapy as a treatment option. ^{12,13} In this study, we aimed to fill this knowledge gap by exploring NSCLC patients' perspectives on hospital facilities and environment, their beliefs about alternative therapies, views on chemotherapy, and changes in life after cancer diagnosis, including treatment costs. Therefore, a semi-structured interview method was applied in the current study to explore the experiences and side effects felt by patients with NSCLC after receiving chemotherapy.

Patients and Methods

Study Design

In the current study, semi-structured guideline-based, face-to-face interviews were conducted to explore patients' personal experiences and the side effects, felt due to chemotherapy. This study was designed to understand personal experiences, besides capturing new insights which would help the researchers in obtaining data on patients' experiences that could not be captured through a quantitative study. The study was conducted from June 2021 to June 2022 in accordance with the Declaration of Helsinki principles and approved by research ethics committee of the Faculty of Pharmacy, the University of Lahore (21-0014). Prior to their participation in the study, written informed consent was obtained from all study participants. Additionally, any future publications resulting from the study will protect the identities of the participants and ensure their confidentiality.

Study Site

The University of Lahore Teaching Hospital, located in Lahore, Pakistan, was established in 2015, 400 open beds with more than 2500 employees working in different medical departments. Medical oncology department received 160 plus new patients per annum in 2021.

Participants with Inclusion/Exclusion Criteria

NSCLC patients were only included (A) patients with histologically confirmed, according to TNM staging criteria set by UICC¹⁴ and (B) patients with under treatment of chemotherapy (experienced at least one cycle of chemotherapy). NSCLC patients who received (A) adjuvant chemotherapy, (B) chronic illness or hematological disease, (C) recently diagnosed, (D) language issue, and (E) advanced-stage (IV) were excluded, and rate of drop-out patient was 51%. Based on inclusion and exclusion criteria, a total of 22 patients (3 males, 19 females) with NSCLC were interviewed by a research assistant at The University of Lahore as shown in Figure 1. The staff nurse asked those patients to participate in the interviews. The clinical pharmacist provided complete information about the study's aim, the voluntary nature of consent, data collection, and, data processing. Confidential and anonymous handling of all personal data was assured. Some patients were escorted by relatives during the interview. Most patients were interviewed in the time between the chemotherapy in the oncology outpatient day clinic. All interviews were conducted from June 2021 to June 2022.

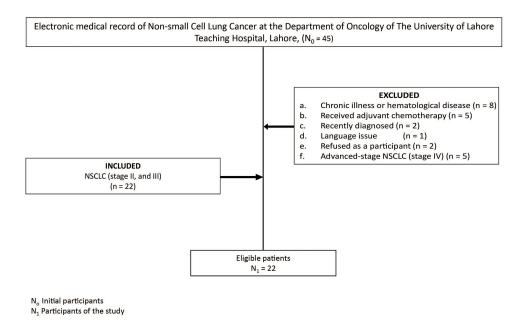


Figure I Procedural flowchart of the study.

Data Collection

The basis for conducting interviews with patients and relatives was semi-structured, pilot-tested interview guides. The interview topic guide was developed based on the Ottawa Decision Support Framework (ODSF), and patients were also allowed to raise any issues of concern to explore the new arising question. The duration of the interviews ranged from 25 to 80 min. The interviews were performed with patients/relatives separately to minimize response bias in a private room in the hospital. The interviews were conducted according to questionnaire (Supplementary Data 1). Each study participant was assigned a unique numeric identifier for anonymization purposes during data analysis.

Statistical Analysis

Data were presented with frequencies and percentages or median for socio-demographic characteristics, clinical characteristics and treatment outcomes.

Results

Patients' Characteristics

The demographic details are seen in Tables 1–3. A total number of 22 patients (3 males, 19 females) with NSCLC participated in this study. The patients with NSCLC were in stage 2(11) and stage 3(11).

Themes

Five key themes were identified from the qualitative analysis: Hospital facilities and environment, Patients' beliefs in alternative treatments, Presenting a positive/negative face (Sharing experience/Viewpoint of treatment), Life is for living, and Health insurance coverage.

Theme I. Hospital Facilities and Environment

Most of the patients could reach the treatment centers within 10 minutes to 1 hour and had not much difficulty in accessing medical care. They found medical staff including doctors, nurses, and clinical pharmacists, very helpful in terms of communication and had built a strong trust in them. One participant mentioned how helpful the healthcare workers were, as they were listening very patiently and going through every detail. Most of the participants appreciated the staff's guidance in their difficult times.

Table I Individual Characteristics of Studied Participants

Patients	Age (Years)	Gender	Weight (kg)	Height (m)	Ethnicity	Education	Residence	Smoking	Drinking	Lifestyle Status	Family Members	Monthly Income/Month (PKR)
Patient I	43	Male	65	1.57	Punjabi	SE	Rural	Yes	No	Hygiene	5	<15,000
Patient 2	72	Female	60	1.62	Punjabi	HSE	Urban	No	No	Hygiene	4	16,000–30,000
Patient 3	68	Female	69	1.59	Saraiki	Bachelor	Rural	No	No	Hygiene	3	16,000–30,000
Patient 4	53	Female	62	1.65	Punjabi	UE	Rural	No	No	Hygiene	2	31,000-45,000
Patient 5	51	Female	86	1.63	Punjabi	Bachelor	Urban	No	No	Hygiene	5	31,000-45,000
Patient 6	49	Female	70	1.77	Saraiki	Bachelor	Urban	No	No	Hygiene	10	16,000–30,000
Patient 7	45	Female	68	1.59	Saraiki	Bachelor	Urban	No	No	Hygiene	4	31,000-45,000
Patient 8	56	Female	70	1.57	Saraiki	Bachelor	Urban	No	No	Hygiene	4	>100,000
Patient 9	41	Female	72	1.72	Pashto	Bachelor	Urban	No	No	Hygiene	3	<15,000
Patient 10	43	Female	59	1.56	Punjabi	SE	Rural	No	No	Poor	4	31,000-45,000
Patient 11	39	Female	74	1.54	Punjabi	Bachelor	Urban	No	No	Hygiene	6	16,000–30,000
Patient 12	60	Male	85	1.76	Pashtun	Bachelor	Urban	No	No	Hygiene	4	60,000–75,000
Patient 13	65	Female	81	1.58	Saraiki	UE	Rural	Yes	No	Poor	2	31,000-45,000
Patient 14	62	Female	77	1.74	Saraiki	UE	Rural	No	Yes	Hygiene	3	31,000-45,000
Patient 15	46	Female	71	1.54	Punjabi	HSE	Urban	No	No	Hygiene	4	16,000–30,000
Patient 16	53	Female	67	1.59	Punjabi	UE	Rural	Yes	No	Hygiene	3	31,000-45,000
Patient 17	42	Female	65	1.69	Punjabi	HSE	Urban	No	No	Hygiene	4	<15,000
Patient 18	72	Male	88	1.78	Saraiki	Bachelor	Urban	Yes	No	Hygiene	4	31,000–45,000
Patient 19	69	Female	78	1.71	Saraiki	UE	Rural	No	No	Poor	6	<15,000
Patient 20	68	Female	69	1.57	Saraiki	Bachelor	Urban	No	No	Hygiene	4	16,000–30,000
Patient 21	47	Female	59	1.59	Punjabi	Bachelor	Rural	Yes	No	Hygiene	3	31,000-45,000
Patient 22	45	Female	60	1.73	Punjabi	HSE	Urban	No	No	Hygiene	2	<15,000

Table 2 Sociodemographic Data of Selected Patients and Studied Variables

Variable	Category	Patients (n)	Patients (%)	Median
Age (years)	≤50	10	45	52
	>50	12	55	
Gender	Male	3	14	
	Female	19	86	
Weight (kg)	≤65	7	32	69.5
	>65	15	68	
Height (m)	≤1.65	13	59	2.57
	>1.65	9	41	
BMI (kg/m²)	<25	8	36	26.6
	>25	14	64	
Education (Years of schooling)	≤8	13	59	
	>8	9	41	
Residence	Urban	13	59	
	Rural	9	41	
Smoking habit	No	17	77	
	Yes	5	23	
Lifestyle status	Hygiene	19	86	
	Non-hygienic	3	14	
Alcohol drinking habit	Yes	I	5	
	No	21	95	
Family members	≤5	19	86	4
	>5	3	14	
Household income (PKR)	<50,000	15	68	
	>50,000	7	32	

Abbreviation: PKR, Pakistani rupee.

Table 3 Disease Variables and Its Related Knowledge of Studied Participants

Variable	Category	Patients (n)	Patients (%)	
Cancer type	Squamous cell	6	27	
	Adenocarcinoma	15	68	
	Other	I	5	
Stage of NSLC	Stage 2	П	50	
	Stage 3	П	50	

(Continued)

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Table 3 (Continued).

Variable	Category	Patients (n)	Patients (%)
Treatment	2 Drugs	13	59
	3 Drugs	9	41
Duration	<2 Years	14	64
	>2 Years	8	36
Treatment cost beared by	Hospital fund	15	68
	Insurance	4	18
	Self	2	9
	Others	I	5
Disease knowledge	Yes	12	55
	No	10	45
Treatment knowledge	Yes	13	59
	No	9	41

I was impressed by the way they treated me. They were extremely nice and trying their best so I won't have any difficulty

They are helpful and supportive and guided us completely. Yes, I completely trust them

However, few patients were not satisfied with the staff because they had difficulties in communication with the medical staff probably due to patients' poor knowledge about the disease and medications. The medical teams' attitudes and behavior also cause a major impact on patient care. Some doctors were in a rush, thus leading to inadequate guidance and care for patients.

They are good but they should communicate more effectively

Not satisfied with them due to their inconvenient behavior

Considering the above information, the participants had mixed (positive and negative) impressions about the care they received. Most of the patients were comfortable and satisfied from care facility but 9 out of 22 participants had difficulties in access to medical care and treatment.

Theme 2. Patients' Beliefs in Alternative Treatments

Some NSCLC patients were using complementary medicines in addition to chemotherapy. Many of them took tea, juices, etc, while a few of them also preferred alternative traditional treatment methods such as Homeopathy, Ayurveda, Unani, and Acupuncture. Some patients believed that they are very effective while few had no idea about them. The number of NSCLC patients who took alternative treatments was 7 out of 22. Their educational levels were outstanding as well. One participant had completed secondary education, two of them had completed high school, and four of them had bachelor's degrees. However, six were unemployed and had lesser household income levels ranging from 2 to 4 lakh rupees per annum. They were using such treatments simultaneously with chemotherapy for better results and quicker recovery although some of them did not know if they would work.

However, most importantly, all the NSCLC patients (100%) in the study admitted that western medicine works better than the traditional ones and chose it as their preferred therapy in fighting cancer. That explains their trust in modern medicine compared to the traditional methods.

Theme 3. Presenting a Positive/Negative Face (Sharing Experience/Viewpoint of Treatment)

The NSCLC patient's comprehension and awareness of chemotherapy vary. Some believed that chemotherapy kills cancer cells and some had no idea about it. Six out of 22 did not have an idea about chemotherapy. All of them were residing in rural areas. One had a bachelor's degree, two had learned till high school, and three of them were uneducated. Out of the six patients, one patient had never heard about them before and got to know about chemotherapy at the hospital.

I heard it for the very first time here (Patient 10)

Here are different ideas they had about chemotherapeutic treatment. Many of them believed that they are under cancer treatment, and also to prevent further spread. It is worth mentioning that the unpleasantness of chemotherapy also was in their minds because adverse effects such as fatigue, exhaustion, nausea, vomiting, and hair loss can make chemotherapy unbearable.

Prevent cancer from spreading

A painful cancer treatment

However, 13 NSCLC patients had positive emotions towards chemotherapy, most of them had trust and hope in recovering from cancer, and some of them said they were recovering and were feeling better than before. Optimism, motivation from cancer survivors, healthcare professionals, and their loved ones, and belief in Allah is key to hope for them.

Yes, I'm waiting to get cancer free soon

Yes, I'm highly optimistic

Yes, I am recovering effectively

Nevertheless, others found it tough, since some of them mentioned numerous side effects, and one reported,

No, everything is difficult

Adverse effects of chemotherapy such as anxiety, depression, loss of appetite, hypersensitivity reactions, and difficult and stressful clinic visits for follow-up care make cancer treatment tough for some patients. When asked about the support from the healthcare workers, it was really impressive that they were very satisfied. The psychological support, social support, counseling, listening to them, and respecting their emotions were appreciated by patients, and healthcare workers have won their hearts because the patients believed that it helped to reduce their burden from illness.

They not only treated my disease but also supported me emotionally

They engaged me in different activities that enhanced my health

Sadly, many patients with NSCLC (10/22) were not aware of the adverse effects of chemotherapeutic agents, because the doctors had not provided all the information about them. Two participants of them were uneducated, two of them were educated up to secondary school, 3 participants up to high school, and three had obtained bachelor's degree. Seven out of 10 were residents in rural areas. Communication plays a major role in the medical field and is especially more important in oncology. A strong doctor–patient relationship would create a better understanding between the two parties, hence building more trust. That was well said by P2, about the health care providers not only providing cancer treatment but also enhancing their emotional well-being.

Along with treatment, they provided psychological and spiritual therapy

Amidst several physical, psychological, social, and financial difficulties due to cancer itself and chemotherapy, they were happy to share their experience with others, because they had an optimistic attitude. As one patient mentioned, "There is

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hope". Many of them mentioned maintaining trust in doctors and taking the medications prescribed by them. The importance of a healthy, balanced diet and also a positive self-image to fight the disease should not be forgotten.

All you need is strength to fight this disease along with prayers

Along with treatment sessions, eat healthy

Don't use medicines other than those prescribed by your doctor.

Theme 4. Life is for Living

The participants admitted that their lives have changed a lot more, compared to it before cancer. Some found it more difficult, yet they were optimistic and cherished how precious life was. Some of them (5/22) fought cancer well and they did not feel much difference in their lives. Four of the above five patients had stage 2 and 3 NSCLC.

No doubt life nowadays is very difficult as compared to prior one but I'm highly optimistic

Life before cancer did not mean a lot to them. It was just about managing their day-to-day activities, but cancer taught them an important lesson about the value of life and what it means. Being diagnosed with NSCLC cancer is grievous, life-changing news. From that moment onwards, they have been undergoing a series of changes in their lives. Now they have realized that life is for living and they love to live more, and are happier, than ever before.

Before cancer, life was just about daily routines. After receiving an NSCLC cancer diagnosis, I came to know how precious life is.

Most of the participants admitted that it was difficult to adapt to the new routine. Therefore, they had to change accordingly. Most of them became stronger and had the fortitude to fight the disease while the family members, their children, and the people around them were the pillars of hope. They also have a strong belief in their God, ALLAH that helps them spiritually to manage to live their life during this difficult period.

Due to my strength, it did not affect me that much

ALLAH gave me strength to face the situation

Ten of 22 patients were not aware of the disease before, and some others had a good idea while some had heard about it. They got to know about their diagnosis from their family doctor or the physician. However, not surprisingly, 3 of 22 participants were not aware of their disease till the last session of treatment. All the participants mentioned that they had to adjust their lifestyle to suit their new routine. One patient reported that he/she was strictly following the diet and avoiding unhealthy habits at that time (P2). They also commented about their health status very gladly, because they were getting better, and feeling good and healthier.

I'm getting healthier now so I'm fine with all this situation

Life with cancer is full of restrains. Not being able to do your day-to-day activities alone, not having an appetite to eat your favorite foods, not being able to do the things you love such as going out and enjoying yourself with your friends, and not having the physical strength to even walk a few steps but having to quarantine yourself in a single room in a scare of getting infections is so hectic. However, as every dark cloud has a silver lining, there is always space for positive thoughts.

Life with restrictions is not good but I'm healing so that's the positive point

They know that they are healing. Although being diagnosed with NSCLC was a hard pill to swallow, in the end, after going through months and years of suffering from cancer and its aftermaths, now it is not much more difficult because they are recovering now.

It is very hard to accept this fact, but the truth was that. So, I accept it. I am feeling better day by day.

Nonetheless, both the disease and adverse effects of treatment leave them in all sorts of hardship. In addition, they keep getting infections due to depleted immunity. These cause not only physical but also psychological sequelae. Some participants reported that their health was deteriorating and even if they were physically better, depression had caused a big impact on their health.

It's very difficult for me as my health is keep on deteriorating

I'm much better now but the phase of depression is quite hard.

Theme 5. Health Insurance Coverage

When someone is diagnosed with cancer, one of the biggest challenges is the financial burden. We inquired them about the costs for treatment and their health insurance coverage. Fifteen of 22 patients benefited from the hospital's fund, four had covered the expenses by their income, and three of them used their savings and insurance coverage. Almost all of them reported that the cost was high while some patients who were supported by the hospital's fund were not quite aware of the expenses. Patient 8 reported that it was affordable for him/her and patient 12 admitted that it was high but manageable. Eighteen of 22 had no health insurance, three had public insurance, and only 1 patient had urban insurance. However, none of the insurance policies covered all the expenses but most of the cost. Unless the hospital's fund covered the payments, a patient him/herself had to pay around Rs.100,000–150,000 a month.

Discussion

Many patients are undergoing chemotherapy for various types of cancers, and they have different experiences. This study revealed such experiences in NSCLC patients and also what they had in their minds about chemotherapy before undergoing treatment. Different types of drugs are used for each type of cancer and therefore the effects of them on patients vary significantly.¹⁵ In this study, the majority of NSCLC patients were affected by the adverse effects of chemotherapy such as fatigue, exhaustion, loss of hair, and vomiting. The analysis also indicates that some patients have difficulty in access to care. The ease of access to care is one of the most important aspects of a healthcare system. The quality of the healthcare system depends on factors such as behavior, clinical care, social and economic environment physical environment, and communication. The importance of communication between the patient and the health staff is very commonly emphasized. It is quite evident that a cancer patient should have exposure to proper counseling and psychiatric assessment.¹⁶ The patient's severe illness itself can lead him/her to disorders such as depression, anxiety, etc.¹⁷ Therefore, the doctors and the other staff should have a good understanding of their patients and should have a very good rapport with patients, and should make sure to listen well and help them.¹⁸

Since chemotherapy is unbearable at times, many NSCLC patients try different kinds of alternative treatments in addition to chemotherapy. Some patients were using them, despite not knowing their effects and success. However, it is difficult to show the relationship between the use of such medications and the educational background or socioeconomic status of the patients. Although they might alleviate their adverse effects, it should be studied about the effectiveness of chemotherapy when such alternatives are used at the same time. Drug—to—drug/herb interactions are an example because most of them are traditional techniques and they lack any scientific evidence. Some interactions can be life-threatening, as reported in the previous articles.

The knowledge of patients regarding chemotherapy was not quite satisfactory. Some of them were not aware of chemotherapy or its adverse effects. Among these, most of them were belong to rural areas, which might indicate that they have limited access to resources providing information. However, such poor knowledge of an NSCLC patient is not acceptable and it means the patient does not have an idea regarding what is being administered to their body. The oncologists, other physicians, pharmacists, and the supportive staff bear the responsibility of educating the patients regarding the chemotherapeutic regimen and its adverse effects of them. Patients In addition, patients should also be instructed on how to deal with them and prescribed medications to overcome such adverse reactions.

After all, life is for living. Life with cancer is a different and difficult living style. The majority of the participants in the study had to change their relationships with others during ongoing treatment. Stressful clinic visits for follow-up

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appointments, repeated injections of chemotherapy and seeing your hair fall off, and more numerous changes in your health, and last but not least, staying alone inside a room during chemotherapy is not pleasing at all.^{30–32} Anyhow, that's "our new life with cancer". Living with a new lifestyle can be quite challenging. Most of the participants in our study had adjusted themselves very well according to the situation because psychological strength is much more important prior to fighting with stressful life especially cancer.³³ While seeing their health deteriorating, they held their nerve strong till they see themselves out, for a bright future. All of the participants were agreed "how precious life is". Most of them have hopes for their new life after cancer.³⁴ However, those who still cannot cope with their worsening health, they fell more health problem. So, physicians should also look psychological aspects of the patients, adequate care and arrange experience sharing sessions so that the patients would be mentally fit.³⁵

Cancer patients, regardless of the type of cancer they acquire, face a huge financial burden.^{36,37} The expenses for chemotherapy, hospitalization costs, etc are some of them.³⁸ In the group of participants we interviewed, many benefited from the hospital's fund and were fortunate to receive cancer treatment without any distress. However, the purpose of this theme is to recognize how difficult it is for a patient being diagnosed with cancer but having no insurance or savings adequate to cover the expenses in a situation where there is no hospital fund.^{39,40} Access to healthcare should be to be universal. The new healthcare systems should find a way to provide care to such patients without delay at the time it is most needed.⁴¹

There are a few limitations in the current study. Patients who were willing to participate in this study were more open to expressing their feelings and experiences while on chemotherapy. Those who refused may have other views on the side effects. Additionally, those who are doubtful of chemotherapy or discontinued chemotherapy earlier were not available for interview. These patients may have different views on chemotherapy compared to patients who completed chemotherapy. Nonetheless, the qualitative semi-structured interviews were conducted about various patients' experiences and side effects related to the use of chemotherapy for NSCLC.

Conclusion

The NSCLC patients undergoing chemotherapy have different experiences which change from one to another. The common problems are not being aware of the adverse effects of chemotherapy and inadequate support to manage the side effects. It is very important to develop good communication skills in the healthcare workers so that patient care will be much improved. As well as, more attention in research should be focused on alternative medications and their use complementarily to chemotherapy. The experiences of patients who had been cured of cancer would be worthwhile for cancer patients because life with cancer is best understood by someone who suffers from cancer. This study made its maximum efforts to reach closer to the minds of patients with cancer who are undergoing chemotherapy to understand their perceptions.

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Disclosure

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