Burden of Symptoms and Symptom Experience of Filipino Patients with Myeloproliferative Neoplasm: A Qualitative Phenomenological Approach

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ABSTRACT

Background. Myeloproliferative neoplasms (MPN) are a heterogeneous group of disorders characterized by the cellular proliferation of one or more hematologic cell lines. Patients with MPN who are Philadelphia-negative such as those with Polycythemia Vera (PV), Essential Thrombocytosis (ET), or Myelofibrosis (MF) experience a cluster of symptoms related to the disease activity which can affect their quality of life.

Objectives. This study aimed to explore the symptoms and symptom experience as well as lived experience of Filipino patients with MPN using a qualitative phenomenological approach to get a deeper understanding of the disease symptomatology.

Methods. Twenty-three patients with myeloproliferative neoplasms were purposively selected according to: 1) type of MPN (PV, ET, MF) 2) status of MPN disease (newly diagnosed vs. chronic) 3) age (≤50 years old; >50 years) and 4) sex (male vs. female). The investigators conducted key informant interviews using a semi-structured interview guide. Interview scripts and narratives were transcribed and analyzed using categorical aggregation and thematic analysis.

Results. Twenty patients proceeded with the interview (8 PV, 6 ET, 6 MF). The meta-themes identified were 1) symptom experience and 2) disease perception. Three sub-themes under symptom experience were a) heterogenous and complex symptomatology; b) dynamic nature of symptoms; c) living and coping with symptoms. Three sub-themes under disease perception were a) struggle with the concept of the disease; b) anxiety and uncertainty; c) acceptance and hope. The most common symptoms experienced by the patients were fatigue, bone pain, and abdominal discomfort. Vascular symptoms specifically headache, numbness, and problems in concentration were commonly reported by patients with PV. Fever and weight loss were the least common. Sources of anxiety/uncertainty include the unpredictability of symptom occurrence and blood counts, the burden of taking maintenance medications, the financial burden of living with MPN, and the unpredictability of disease and complications.

Conclusion. Patients with MPN had heterogenous, co-occurring, and dynamic symptoms which affected their overall productivity both at home and at work. Patients with MF had the most symptom burden while

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patients with ET had the least. This study provided valuable insights on disease perceptions, sources of anxiety, and coping mechanisms of patients with MPN. A deeper understanding of the symptom experience and disease perceptions of the patients will enhance the physician-patient interaction especially when discussing management options.

Keywords: myeloproliferative neoplasms, symptom burden, quality of life, symptom experience, qualitative study

INTRODUCTION

Myeloproliferative neoplasms (MPN) are a heterogeneous group of disorders characterized by cellular proliferation of one or more hematologic cell lines. Patients with Philadelphia-negative MPN such as those with Polycythemia Vera (PV), Essential Thrombocytosis (ET), or Myelofibrosis (MF) experience a series of problems related to the disease activity, symptomatology, and thromboembolic complications. Several studies have shown that these diseases are more than just myeloproliferation. In a prospective interventional study using interferon-alpha, Merup et al. reported that 30% of patients with PV and ET had baseline symptoms of headache, muscle pain, fatigue, and depression.[1] A large online survey conducted by Mesa et.al reported fatigue to be the most common symptom (80.7%) among patients with MPN. This survey provided baseline information on constitutional symptoms experienced by patients with MPN and underscored the need to incorporate these symptoms in quality of life assessment tools.[2] Understanding the symptom burden and symptom experience of patients with MPN is needed in developing a comprehensive wholistic management plan that addresses the physical and emotional aspects of this chronic disease such as MPN. To date, there is no published data on the symptom burden of Filipino patients with MPN. Hence, this multi-center qualitative study aimed to determine the symptoms and symptom experience as well as lived experience of Filipino patients with MPN to get a deeper understanding of the disease symptomatology.

METHODS

Study Population and Design

This multi-center qualitative study used the phenomenological approach to explore symptom experience and symptomatology felt by Filipino patients with MPN. The investigators identified consecutive MPN patients by purposive sampling from the patient census of two private tertiary hospitals and two public tertiary hospitals. The investigators used maximum variation sampling, a subtype of purposive sampling wherein participants with the set of criteria or characteristics which may affect the phenomenon of interest were selected. The four sampling criteria used were: 1) type of MPN (PV, ET, MF); 2) status of MPN disease (newly diagnosed vs. chronic); 3) age (≤50 years old, >50 years) and 4) sex (male vs. female). At least three patients per sampling frame were recruited. A total of 20 patients were eventually interviewed from December 2021 to May 2022 using a semi-structured interview guide with ten open-ended questions. (Appendix 1).

All interviews were arranged to accommodate the participants' availability and conducted either face-to-face or by online interview. An interview guide was given in advance to the participants, which also served as a guide during the actual interview. Participants were encouraged to talk freely and answer using their own words and they were informed that there were no right or wrong answers. Interviews lasted for 30-45 minutes each were conducted by the main investigator and research assistant trained on doing key informant interviews (KII). At least 2 interviewers were present during the KII to balance if and when one of them was part of the medical team taking care of the patient. After the interview, the interviewer provided de-briefing and emotional support for patients who developed emotional distress.

Interviews were recorded on the investigator's laptop/hard drive. Recordings were transcribed verbatim by the researcher or research assistant. Soft copies of the transcriptions were also kept in a secure storage device. Patient identifiers were removed in each recording and corresponding transcription, and patient code was used. In addition, each interview was saved in a digital folder in two locations protected by a passcode providing duplicate sources of original material in case a back-up was needed.

Mode of Analysis

Interview scripts and narratives were transcribed and analyzed using categorical aggregation and thematic analysis. This method ensured that the transcripts were read and re-read, allowing for a thorough understanding of the data. The results were analyzed manually using Colaizzi's method, a well-established approach in qualitative research that involves the identification of meaning units from participants' sharing of their experiences.[3]

The meaningful units of data that emerged from the transcripts were derived and highlighted from each participant's sharing of their lived experiences. These meaningful units were then coded with descriptive words. The different codes were organized in hierarchical levels, and category systems were created.

Upon reviewing the categories, a series of themes emerged. These themes provided a deeper understanding of the participants' experiences and perceptions, allowing for a more comprehensive analysis of the data. The themes identified were used to draw conclusions and provide insights into the research question.

To establish rigor and trustworthiness, transferability, member checking, and dependability were employed as defined by Lincoln and Guba.[4] Transferability, referring to external validity, was facilitated through the use of purposive sampling and inclusion of extensive quotations in the analysis. This approach ensured that the data was representative of the population under study, increasing the generalizability of the findings. Member checking was done to increase credibility, facilitated by asking a subject to verify the completeness and accuracy of an interview transcript. Dependability, referring to reliability, was ensured by providing an audit trail for the research process to be logical, traceable, and clearly documented. This approach allowed for a more transparent and replicable research process, increasing the reliability of the findings.

Ethical Considerations

The study protocol was approved by the Department of Health - Single Joint Ethics Review Board (SJREB 2021-91). The individual ethics review board of the four hospitals also provided technical and ethical approval. Informed consent was obtained from all study participants. All participants were assured of confidentiality and anonymity.

RESULTS

A total of 23 patients were recruited for the interview but only 20 proceeded with the study. Two did not consent due to personal reasons and one had difficulty in scheduling an interview and eventually withdrew consent. Of the 20 patients interviewed, 8 had PV, 6 with ET, and 6 with MF. Table 1 shows that most of the patients were females with an age range of 24-72 years old. More than half of the patients have been diagnosed with MPN for at least 3 years, ranging from 1 year to 15 years while seven were newly diagnosed. Fourteen patients were from the two private tertiary hospitals and 15 completed at least a secondary education and above.

Table 2 shows the individual patient characteristics and symptom burden according to type of MPN. Hypertension was the most common comorbidity and three patients had a history of thromboembolic complications. The most common symptoms experienced by the participants were fatigue and bone pain, followed by abdominal discomfort, headache, and numbness. Problems in concentration and pruritus were the third most common symptoms. Early satiety, weight loss, and fever were the least common. Three patients with ET were asymptomatic.

Table 3 shows the distribution of symptoms according to the type of MPN. Patients with myelofibrosis had more constitutional and spleen symptoms while patients with PV experienced more vascular symptoms like headache and numbness. Patients with essential thrombocytosis were least symptomatic or did not have symptoms at all upon diagnosis.

Figure 1 summarizes the meta-themes identified during the interviews: 1) Symptom Experience and 2) Disease Perception. Three sub-themes were identified under *Symptom Experience*: a) Heterogeneous and complex symptomatology; b) Dynamic nature of symptoms; and c) Living and coping with symptoms. There were three sub-themes under *Disease Perception* namely: a) Struggle with the concept of the disease; b) Anxiety and uncertainty; c) Acceptance and hope.

Below are the description with narratives for each theme and Appendix 2 contains additional narratives from patients.

Symptom Experience

The patients enumerated their symptoms during the time of diagnosis by recalling and narrating the story on how they were diagnosed. Then they were asked to enumerate their current symptoms. They explored the symptom experience with regard to severity, character of symptoms, effect of symptoms to daily life, symptom exacerbation, and coping mechanisms.

Heterogeneous and Complex Symptomatology

Upon diagnosis, most patients (n=17) were symptomatic. Three patients with ET were asymptomatic and were diagnosed based on an incidental finding of an abnormality

Table 1. Demographic and Disease Characteristics of Patients Interviewed

	Polycythemia Vera (n=8)	Essential thrombocytosis (n=6)	Myelofibrosis (n=6)	Total (N=20)
Age				
20-50	5	2	2	9
51 and above	3	4	4	11
Sex				
Female	5	4	4	13
Male	3	2	2	7
Educational attainment				
Primary	2	0	1	3
Secondary	2	0	2	4
Vocational	1	1	0	2
Tertiary	3	5	3	11
Disease status and duration (range)				
Newly diagnosed	4 (2-6 months)	2 (3-5 months)	1 (6 months)	7
Chronic patient	4 (2-9 years)	4 (2-12 years)	5 (2-15 years)	12
Type of healthcare setting				
Private	5	4	5	14
Public	3	2	1	6

Table 2. Disease Characteristics and Symptoms of Individual Patients with MPN

Patients (N=20)	Sex/ Age	Disease status/ Duration of disease	Co-morbid conditions	History of thrombo-embolic complications	Symptoms	Treatment regimen
Polycythemia Vera (n=8)						
PVP1	58/F	Chronic patient (CP) /4 years	HPN	None	Fatigue Abdominal discomfort Pruritus Body pain Headache	Hydroxyurea, aspirin
PVP2	44/M	Newly diagnosed (ND) /6 months	HPN	None	Back pain Body pain Numbness Headache	Hydroxyurea, clopidogrel
PVP3	40/F	CP/2 years	None	Yes (ischemic stroke)	Headache Nausea and vomiting	Hydroxyurea, aspirin
PVP4	64/M	ND/3 months	HPN	None	Fatigue Body pain Headache	Hydroxyurea, clopidogrel
PVP5	46/F	CP/4 years	HPN	None	Fatigue Abdominal discomfort Inactivity Problems in concentration Night sweats Weight loss Body pain Headache Dizziness	Hydroxyurea, clopidogrel
PVP6	48/M	ND/2 months	HPN,DM	None	Problems in concentration Numbness Headache	Hydroxyurea, clopidogrel
PVP7	46/F	ND/6 months	None	None	Problems in concentration Numbness	Aspirin
PVP8	68/F	CP/9 years	HPN	None	Fatigue Early satiety Abdominal discomfort Problems in concentration Bone pain	Hydroxyurea, aspirin
Essential Thrombocytosis (n=6)						
ETP1	68/M	CP/2 years	Prostate cancer, in remission	None	None	Hydroxyurea, clopidogrel
ETP2	52/F	CP/12 years	HPN, DM	None	Body pain Numbness	Hydroxyurea, clopidogrel
ETP3	44/F	CP/4 years	HPN	Yes (ischemic stroke)	Dizziness Nausea and vomiting Numbness	Hydroxyurea, aspirin, anagrelide
ETP4	54/F	ND/3 months	HPN	None	None	Anagrelide, clopidogrel
ETP5	65/F	CP/5 years	HPN,DM	None	Fatigue Problems in concentration Pruritus Numbness	Hydroxyurea, aspirin
ETP6	48/M	ND/5 months	None	None	None	Clopidogrel

Table 2. Disease Characteristics and Symptoms of Individual Patients with MPN *(continued)*

Patients (N=20)	Sex/ Age	Disease status/ Duration of disease	Co-morbid conditions	History of thrombo-embolic complications	Symptoms	Treatment regimen
Primary Myelofibrosis (n= 4)						
MFP1	72/M	CP/2 years	HPN	None	Fatigue Body pain Pruritus Fever Headache	Ruxolitinib, anagrelide, clopidogrel
MFP2	72/F	CP/4 years	HPN	None	Fatigue Inactivity Abdominal discomfort Back/bone pain	Hydroxyurea, erythropoietin
MFP3	32/M	ND/6 months	None	None	Night sweats Pruritus	Ruxolitinib
MFP4	24/F	CP/4 years	Cirrhosis	Yes (Portal vein thrombosis)	Fatigue Early satiety Abdominal discomfort Inactivity Problems in concentration Night sweats Bone pain Weight loss	Clopidogrel
Secondary Myelofibrosis (n=2)						
MFP5	68/F	CP/5 years/ ET for 12 years; post-ET MF for 5 years	None	None	Fatigue Abdominal discomfort Bone pain Weight loss	Hydroxyurea, thalidomide
MFP6	69/F	CP/PV for 15 years; post-PV MF for 2 years	HPN	None	Fatigue Abdominal pain	Ruxolitinib, clopidogrel

Table 3. Symptoms Experienced by Patients with MPN

Symptoms	Polycythemia Vera (n=8)	Essential Thrombocytosis (n=6)	Myelofibrosis (n=6)	Total (N=20)
Fatigue	4	1	5	10
Body/back/ bone pain	5	0	4	9
Abdominal discomfort/pain	3	0	4	7
Headache	6	0	1	7
Numbness	3	3	0	6
Problems in concentration	3	1	1	5
Dizziness	1	1	0	2
Pruritus	1	1	2	4
Early satiety	1	0	1	2
Nausea and vomiting	1	1	0	2
Weight loss	1	0	2	3
Inactivity	1	0	2	3
Night sweats	1	0	2	3
Fever	0	0	1	1
Asymptomatic	0	3	0	3

Myeloproliferative Neoplasms

Meta-theme 1: Symptom Experience

Heterogenous and complex symptomatology
1. Patients with MF and PV were more symptomatic.
2. Constitutional, vascular and abdominal symptoms were common and co-occurring.
3. Patients with ET may be asymptomatic even with uncontrolled blood counts

Dynamic nature of symptoms
1. Symptoms fluctuated or occur within the day which may be in varying intensities.
2. Fluctuations and exacerbations were unpredictable.

Living and coping with symptoms
1. Symptoms affected productivity at home and at work such that adjustments had to be made in their routine work.
2. Patients with MF experienced the most effect.

Meta-theme 2: Disease Perception

Struggle with the concept of the disease
1. Patients have difficulty understanding that PV, ET and MF are forms of blood cancer.
2. Patients refer to the disease as “sakit sa dugo”.

Anxiety and uncertainty
1. Unpredictability of symptom occurrence and blood counts
2. Burden of taking maintenance medications
3. Financial burden of living with MPN
4. Unpredictability of the disease and complications

Acceptance and hope
1. Hope for cure is anchored on faith and renewed spirituality.
2. Patients regard PV and ET as a chronic disease with no cure, not as a blood cancer, while patients with MF accept it as a form of cancer which can transform to leukemia.

Figure 1. Hierarchical Map of Themes.

in routine laboratory tests, which led to the diagnosis of their disease.

> ***“It was incidental finding, nagkaroon ako ng mataas na blood pressure. Nagpa-blood chem ang doctor ko. Wala akong naramdamang sintomas, pero kinabahan ako nang makita kong 1.3 milyon ang platelet ko**. (“It was an incidental finding; I had elevations in blood pressure. So my doctor requested for blood tests. I didn’t feel any symptoms, but I was anxious when I saw my platelet was 1.3 million.” [ETP4/54/F/ND])*

The patients with Myelofibrosis and PV were more symptomatic. The symptoms were described as complex, multiple non-specific symptoms which caused anxiety, polypharmacy, and sometimes emergency department visits during symptom exacerbation. As they started living with their disease, the participants described their symptoms as ranging from no symptoms at all to multiple co-occurring symptoms.

> ***“Marami akong sintomas noon, pasulpot-sulpot na lagnat, pangangati, pananakit ng ulo at pananakit ng katawan. Palagi akong nagpupunta sa ospital dahil sa matinding pananakit ng katawan/ulo. Binibigyan nila ako ng iba't ibang uri ng pain reliever na nagbibigay ng pansamantalang ginhawa. Pabalik-balik ako sa ospital; wala silang makitang dahilan...Pagod na din ang mga doktor. Noong hindi talaga ako ma-diagnose, pumunta ako ng Manila at kumuha ng second opinion.” (**“I had a lot of symptoms before--intermittent fever, itching, headaches, and body aches. I always go to the hospital because of bouts of severe body/headache. They give me different types of pain relievers that provide temporary relief. I go back and forth to the hospital; they can't see any cause. The doctors were tired too. I went to Manila for second opinion.” [MFP1/72/M/CP])*

On average, symptomatic participants had at least 2-8 symptoms occurring at the same time including fatigue, early satiety, inactivity, problems concentrating, night sweats, pruritus, bone pain, fever, and weight loss. In addition, although most participants (17/20) agreed with the MPN symptoms listed in the MPN-symptom assessment form, seven experienced headaches, which was not included in the shortlist.

> ***“Hindi talaga maganda ang pakiramdam ko noon. Laging sumasakit ang ulo ko, nahihilo ako. Malabo minsan ang paningin ko. I feel hot but I don't have fever, I can't understand what's happening to me. Ewan ko ba, sobrang bigat ng katawan ko. Pakiramdam ko ay pagod na pagod ako, kung minsan ay kinakapos ako ng hininga.”** (“I really did not feel well then. My head always hurts, and I'm dizzy. My vision is sometimes blurry. I feel hot but don't have a fever; I can't understand what's happening to me. I don't know; my body is very heavy. I feel very tired; sometimes I'm out of breath.” [PVP1/58/F/CP])*

Dynamic Nature of Symptoms

From the interviews, we noted the dynamic nature of symptoms. The participants experienced fluctuations in the occurrence and severity of symptoms. Fluctuations occurred over hours but resolving within the day; symptoms occurred throughout the day with varying intensities. Participants particularly those with MF noticed an improvement in symptoms when they were taking medications, especially JAK-2 inhibitors, compared to when they were newly diagnosed.

> ***"On and off ang pag-atake ng sintomas… Minsan sa isang araw, bigla akong nakaramdam ng pamamanhid sa mga kamay at mga daliri…"*** *("I have on and off symptoms. Sometimes during the day, suddenly I feel numbness in my hands and fingers." [ETP2/52/F/CP])*

> ***"Ang energy ko kasi ngayon mababa, madali akong mapagod. Pero kumpara dati nung hindi pa ako nag gagamot, malaki ang ginhawa ngayon. Hindi na din ako pabalik balik sa ospital."*** *("My energy is low most of the day; I get tired easily. But compared to when I had not been taking medications, there is a lot of relief now." [MFP1/72/M/CP]")*

Symptoms were not predictable; there were days with no symptoms where they were more productive. Some participants also felt fewer symptoms when their blood counts were within or around normal levels.

> ***"Kapag maganda ang blood levels ko, wala akong mga sintomas tulad ng dati. Wala akong nararamdaman, kung hindi madali lang akong mapagod kahit wala akong ginagawa."*** *("When my blood levels are normal, I don't have the same symptoms as before. I didn't feel anything, except that I just get tired easily even if I'm not doing anything." [PVP1/58/F/CP]")*

Two participants initially diagnosed as PV and ET but now transformed to MF felt their symptoms were worse when their disease progressed. Both particularly mentioned fatigue as the most debilitating symptom which caused the patient with post-PV MF to resign from her current job.

Living and Coping with Symptoms

The participants consistently shared that the disease or symptoms affected at least one aspect of their lives. Eight (8) out of 20 are staying home as unemployed/retirees (6 females and 2 males). They had to give up some household chores or decrease the workload they used to do before due to easy fatigability. Twelve (12) out of 20 who were employed/self-employed experienced a change in employment, decreased work hours, or change in work assignment; some gave up a dream job or retired early.

> ***"Sabi ng boss ko, dahil matagal na rin naman akong may sakit sa dugo…mag early retirement na lang ako at kunin disability benefit ko para makapahinga."*** *("My boss said I have been sick for quite some time, it's best to take disability benefit so that I can rest." [MFP6/69/F/CP]")*

> ***"Noong una, malaking adjustment talaga kasi kailangan kong i-give up yung pag-babarko ko. Akala ko normal lang ako. Bigla na lang nalaman na may sakit ako sa dugo."*** *("At first, it was also a big adjustment. It was all of a sudden that I thought I was normal. Suddenly it turned out that I was sick in the blood so I had to give up my dream. MFP3/32/M/ND")*

Overall, productivity at work, in school or at home was affected in terms of quality and quantity. Their symptoms also affected the social aspect of their lives; some patients mentioned skipping strenuous leisure activities and overcrowded areas, especially during the pandemic.

Coping mechanisms were also explored, including watching television, reading books, taking up a new hobby, and taking care of pets. For some patients, adapting and gaining control of symptoms were eventually achieved by continuously understanding the symptoms, what exacerbates, and what factors offer relief.

> ***"Kapag nararamdaman ko na ang pananakit ng ulo o katawan, handa na ako sa pain reliever/s at pahinga. Dahil nag-e-enjoy ako sa trabaho ko, nakakalimutan ko ang mga sintomas, kapag nakauwi ako at walang ginagawa, mas nararamdaman ko ang mga sintomas".*** *("When symptoms set in, I am ready with my pain reliever/s and rest. Because I am enjoying my job, I forget the symptoms. When I get home and do nothing, I feel the symptoms more." [PVP5/46/F/CP].)*

> ***"Kapag naramdaman ko na ang pagod, humihiga ako, natutulog ako. After that, parang na-recharge na ako."*** *("Once fatigue sets in, I lie down, I sleep. After that, I feel like I'm recharged." [MFP2/72/F/CP])*

Participants self-managed their symptoms; some mentioned taking a walk or light physical activity, short naps, and pain relievers. Some patients ignored their symptoms consciously or unconsciously; avoiding the thought/feeling was their way of coping.

> ***"Hindi ko iniisip ang mga sintomas. hindi ko pinansin. Nagbubusy na lng ako para makalimutan ko."*** *("I don't think about the symptoms. I ignore them. I keep myself busy to forget them." [ETP4/54/F/ND])*

A consistent coping mechanism mentioned by the participants with or without symptoms was surrendering one's illness/symptoms to a higher being they believed in. As a result, most of the patients (16/20) had a better relationship with God. Renewed spirituality was described as becoming more prayerful and lifting all concerns and fears of their disease.

> ***"Nararamdaman ko na mas lumakas ang aking pananampalataya. Mas umaasa ako sa Diyos para maging OK araw-araw."*** *("I feel that my spiritual life became stronger. I depend more on God to be OK every day." [MFP2/72/F/CP])*

They also experienced increased hope through their spirituality leading to higher levels of psychological well-being. One participant also expressed the idea that God may have a purpose for the disease despite the inability to explain the pain or symptoms.

> ***"Hindi ako natatakot sa sakit ko. Bahala na si God. Umaasa lang ako sa kanya. Lalong lumakas ang tiwala ko sa Panginoon dahil ibinigay ko ang buhay ko sa kanya."*** *("I'm not afraid of my illness. It's up to God. I just depend on Him. My trust in the Lord grew stronger because I gave my life to Him." [MFP6/69/F/CP])*

Disease Perceptions

Struggle with the Concept of the Disease

Most of the participants (18/20) initially struggled with the concept of their disease. The participants seem to find it hard to understand the presence or absence of symptoms with the laboratory results. They struggled with the idea of having "blood cancer," yet their symptoms were non-specific, with no visible tumor/mass and no hematomas, which for most Filipinos are the signs of blood cancer. Most of them had to resort to searching for the answers on the internet, which caused more anxiety and confusion.

> ***"Nung una kasi sabi ko ano kaya yun? Kasi hindi talaga ako pamilyar sa PV. Tapos hindi pa sinabi sa akin agad na cancer in blood pala yun na-search ko lang sa internet. Syempre po natakot din ako."*** *("I wasn't told right away that it was cancer in the blood, so I searched on the internet. I felt anxious since I don't have any symptoms like bruises but I read it was cancer." [PVP8/68/F/CP])*

Majority also perceived this as a hereditary disease and tried to look for a family history of blood disease as the main risk factor. Some perceived it as something associated with food intake; they would avoid food that they believe can cause abnormality in blood counts and exacerbate symptoms.

Anxiety and Uncertainty

According to the participants, anxiety and uncertainty arose from several reasons:

Unpredictability of symptom occurrence and blood counts

Some patients curtailed their physical activities and set physical limits due to the symptoms, especially fatigue. The unpredictability of fluctuation of symptoms also affected their work, socialization, and planning of their day-to-day activities.

> ***"Kapag may lakad, kapag alam kong kailangan medyo maglakad ng malayo sabi ko hindi na ako sasama, kayo na lang. Kapag medyo pupunta sa pasyalan nagpapa-iwan na lang ako."*** *("When I know I need to walk more than usual, I skip these leisure activities." [MFP1/72/M/CP])*

Blood counts are essential in the management of MPN. It is the basis for adjusting the dose of medications, assessing the need for non-pharmacologic management like phlebotomy for PV or blood transfusion for MF, such that anticipation of the test results has become a source of anxiety consistently mentioned by patients. The thought of periodic needle pokes elicited negative emotions, especially for patients with PV needing phlebotomy.

> ***"There came a time na yung isang phlebotomy apat na beses akong tinusukan, ayaw lumabas ng dugo ko, malapot daw or maliit daw ugat. Ang sakit ng mga tusok."*** *(There came a time when I needed phlebotomy and I was poked 3x because they had difficulty looking for veins. I fear the pain of the needles." [PVP1/58/F/CP])*

Burden of taking maintenance medications for life

Myeloproliferative neoplasms are life-long diseases, and the study participants have accepted this fact. One of the challenges mentioned was having to take medications for life, especially for the patients who were newly diagnosed. They had to adjust to this new pattern. The burden of medication routine, the complexity of the regimen, and the periodic changes in dosage depending on the blood counts were brought up.

> ***"Nanibago ako, there was a change in my routine. Nadagdagan ng 2 ang gamot ko which I need to take twice a day aside from my anti-hypertensive medications.*** *("I felt the change in my routine. My medication increased by 2 which I need to take twice a day aside from my anti-hypertensive medications." [PVP6/48/M/ND])*

Some participants were concerned about the side effects of the drugs like blackening of the nails, mouth ulcers, hematomas, or bleeding, which caused physical or psychological negative emotions.

> ***"Yung sa gamot ang complain ko lang ay mga singaw, nagkaroon ako ng 20 singaw tapos binigyan ako ng alternate kaso lang very expensive so ni-retain ko na lang. Yung side effect nga lang nag sisingaw ako and pasa-pasa madalas."*** *("The only thing I complain about the medicine is it causes mouth ulcers. I had 20 of them and then I was given an alternative but it was very expensive, so I was not able to buy." [ETP3/44/F/CP])*

Financial burden of living with MPN

Part of the monitoring and management of MPNs is the life-long medication and periodic blood tests, which caused financial burden and anxiety to the patients. Our participants were mostly retired or housemakers with no regular source of income.

> ***"Ineexpect ko unang una pa na medyo magastos itong sakit ko. Kaya ineexpect ko kapag tumatagal ang buhay ko nagiging mas magastos ang buhay ko."***

> *("I expect at first that my illness would be a bit costly. So I think when my life last longer, it will cost us a fortune." [MFP1/72/M/CP])*

Most of them relied on their families to sustain their healthcare expenditures. None had health insurance to cover their medical needs. Retirement pensions and contributions from employed family members were used to augment the cost of treatment. Some of them lost their job, especially the three participants who were seafarers, who could not pursue their profession; instead, they had to divert to self-employment/family-owned businesses. The out-of-pocket expenditure consisted of at least two medications (i.e., hydroxyurea or JAK-2 inhibitor or anagrelide and anti-platelet), blood tests, consultation fees, phlebotomy/blood transfusion, and transportation expenses. Financial problem was also the most significant challenge during the pandemic for most of the patients.

> ***"Ang pinaka-epekto ng sakit ko ay financial, lalo na na-discover nung pandemic. Hindi ako nakasakay sa barko, malaki ang nawala sa amin. Tapos may gamot pa kailangan inumin at mga blood test. Bumalik na lng kami sa probinsya para magtayo ng maliit na negosyo." (****"The biggest impact of my illness was financial, especially that I was diagnosed during the pandemic. I lost my source of income then I need to take medications and blood tests. We just went home to the province and formed a small business." [ETP648/M/ND])*

Unpredictability of the disease and complications

Myeloproliferative neoplasms are at higher risk for thromboembolic complications such as stroke, acute myocardial infarction, and deep venous thrombosis. Almost half of the participants (9/20) mentioned this as a source of anxiety. The unpredictable, sudden, and fatal nature of these vascular events kept the patient constantly on the lookout for signs and symptoms, which can be distressing daily. As a preventative measure, several participants altered their lifestyle and eating preferences. Two participants stated that they had a strong passion for food and that curtailing this aspect was a significant sacrifice. Three out of twenty patients said that the possibility of developing acute leukemia or myelofibrosis was a source of worry. This complication, aside from being unpredictable, is also not preventable.

> ***"Yun pong complication na stroke, yun po kinakatakutan ko. Kaya po ayokong mainitan, natatakot akong lumabas, gusto ko komportable ako."*** *("The complication of stroke, that's what I'm afraid of. I don't want to go to a hot environment, I'm afraid to develop heat stroke, I want to be comfortable." [ETP4/54/F/ND])*

Acceptance and Hope

Most of the participants, particularly those with a family history of cancer, were able to accept the condition easily.

> ***"Natanggap ko naman po kasi yung nanay ko may breast cancer din ako lagi yung kasa-kasama niya. Kumbaga fighter siya kaya ganun din ako. Parang sakit lang yan sabi kong ganun.*** *("I was able to accept it because my mother had breast cancer and I was always with her. She was a fighter and a survivor, so I said I should be too." [PVP8/68/F/CP])*

The younger and productive age group had a longer time to accept the diagnosis since most of them believed themselves to be healthy and suddenly had to deal with a life-long unpredictable disease. They also had to change jobs to accommodate their illness. Three were seafarers who could not get international employment after their diagnosis. One was a college student who had a very traumatic experience with the discovery of her disease but eventually was able to accept it. However, she has fears for her future. Three of the patients were relieved that physicians had finally discovered the condition causing their non-specific symptoms after repeated tests and doctor hopping. Even though their doctors explained the nature of the illness, the hope of a cure was mentioned repeatedly by the patients. And this hope was anchored to their faith and renewed spirituality.

> ***"Hindi naman po. Parang mas na-relieve ako. I don't think so na mahirap siyang tanggapin. Na relieve ako sa nalaman ko na ito pala yung sakit ko. And try to research ano ba ibig sabihin. Hindi naman somewhat mga terminal type ng disease."*** *("I feel more relieved. I don't think it's so hard to accept it. I was relieved to find out that this was my illness. And I tried to research what it means. I'm glad it's not like a terminal type of disease." [ETP5/65/F/CP])*

DISCUSSION

Through in-depth interviews, we were able to explore the symptoms, understand the symptom experience, and how our patients with MPN are living with their disease. Using maximum variation sampling, we were able to get a small representation of old and young patients, newly diagnosed and chronic patients, male and female patients with PV, ET, and MF. Our participants generally experienced heterogenous, complex and co-occurring symptoms such as constitutional, vascular, and abdominal/spleen symptoms. Fatigue was the most common symptom, followed by body/bone pain, then abdominal discomfort, headache, and numbness, while fever was the least or almost not experienced by the participants. These symptoms were consistent with the published studies. The survey of Mesa et al.[2] reported the frequency of symptoms in patients with MPN as follows: fatigue (80.7%), pruritus (52.2%), night sweats (19.2%), bone pain (43.95%), fever (13.7%), and weight loss (13.1%). Another study by Mesa et al.[5] paved the way for the creation of the Myelofibrosis Symptom Assessment Form (MF-SAF) as an objective tool for clinical trials involving JAK-2 inhibitors for MF. Using the MF-SAF, the most common symptoms were fatigue (84%), night sweats (56%), spleen symptoms (54%), pruritus (50%), bone pain (47%), weight loss (20%), and fever (18%). By consolidating all the symptoms for myelofibrosis and other types of MPN, Scherber et al.[6] created the Myeloproliferative Neoplasm Symptoms Assessment Form (MPN-SAF). The form consisted of a total of 17 items. In this study, fatigue was still the most prevalent across all MPN types at 92.7%. Emanuel et al.[7] created a shorter version of the symptom score for ease of use in real-world practice. In this study, the frequency of fatigue was 89%, followed by abdominal symptoms (50-60%), inactivity and problems in concentration (62%), night sweats and pruritus (53%), and fever (18%). Another survey characterized the fatigue of MPN patients as moderate to severe, with an average Brief Fatigue Index (BFI) score of 4.4/10 (SD2.4).[8] Fatigue was more common in the afternoon or evening, with a few hours duration rather than the whole day. One of the notable differences we elicited in our interviews was the higher frequency of headache and numbness (vascular symptoms) and the low frequency of fever experienced by our participants. These observations were also noted in a study that Chinese patients[9], regardless of gender, reported more microvascular symptoms. In contrast, in Western patients, fatigue was the most prominent symptom. The exact reason is unclear though it was attributed to the norms of cultural expression of symptoms and the biologic and clinical difference in MPN disease in different races.

From the interviews, the symptoms were heterogenous both within and between MPN types. Symptom exacerbation was unpredictable but manageable. Associations between symptoms and disease features have been well studied. It was shown that symptoms overlap with other symptoms and closely correlate with other disease features such as laboratory derangements, the presence of vascular complications, mutational status, and risk scores.[10,11]

In our participants, symptoms affected productivity both in their work and home setting. Yu et al. published a survey on the impact of MPN in employment and work status using the Work Productivity and Activity Impairment Specific Health Problem questionnaire (WPAI-SHP) and MPN-SAF TSS. This study showed that approximately half of the 592 employed survey respondents reported a change in employment status because of their diagnosis. The most common impact on employment were 1) change in job (30.2%); 2) "went on medical disability leave" (24.8%), and 3) "had reductions in work hours for at least three months" (21.8%).[12] It was also reported that MPN caused cancellation of planned activities or call in sick to work at least once in the preceding 30 days (cancel planned activities: MF, 56%; PV, 35%; ET, 35%; call in sick: MF, 40%; PV, 21%; ET, 23%).[13]

We observed a struggle in the concept of the disease in most of our patients upon diagnosis. In the MOSAICC study (Myeloproliferative neoplasms: An In-depth Case-Control) by McMullin et al. in 2016, majority of the patients with MPN labelled the disease as a "blood condition" rather than "cancer". This hesitancy may have started with the WHO nomenclature change from Myeloproliferative disorders (MPD) to Myeloproliferative neoplasms (MPN) in 2008. While the acquired clonal nature of the disorders supports the new definition as a form of cancer, patients and physicians alike were hesitant to label the disease as cancer due to its unknown etiology and the heterogenous symptoms and course that the patients experience.[14] This disease perception may have further influenced the patients' and physicians' behavior towards the disease which may warrant further exploration in another study.

The participants' anxiety and uncertainty were largely attributed to unpredictability of symptom occurrence and blood counts, unpredictability of disease and complications, burden of taking maintenance medications for life, and financial burden of living with MPN. This negative impact on the quality of life of patients with MPN was also observed in separate surveys for patients with MPN in the US and the UK. Specifically, both surveys found that any type of MPN had a substantial negative impact on patients' employment status, career potential, and work productivity that are of the same level as other chronic disabling diseases. This finding was observed in all types of MPN whether they were high risk or low risk of complications and similarly between severe and mild symptom burden groups.[15]

Myeloproliferative neoplasms are known to have higher risk for thromboembolic complications such as stroke, acute myocardial infarction, and deep venous thrombosis. Almost half of the participants mentioned this as another source of anxiety. While several of the participants volunteered that they are always on the lookout for signs and symptoms of these complications, there is still the question of proper recognition of such symptoms, timeliness of recognition, and taking action. This is similar to the study done by Chang et al. where a huge gap identified was the ability of patients recognizing their symptoms, relating it to the disease, and describing it to their treating physicians.[16] Blood counts are important in MPN since it is the basis for both pharmacologic and non-pharmacologic management. In a study by Chang et al., both patients and physicians agreed that disease progression and treatment success was defined by symptomatic relief and blood count improvement.[16] This maybe the underlying reason for the anxiety associated with the uncertainty of the results as reported by our study participants. Also, the anticipation of having a blood extraction may add to the anxiety associated with blood counts. Furthermore, while physicians try to probe for symptoms, both physicians and patients are often more comfortable discussing the CBC result. The underlying assumption that the CBC is a more objective parameter of disease control may steer the patient visit discussion to the CBC result, but this does not totally relieve the anxiety brought about by the symptoms experienced by the patients.

While majority of the participants have accepted that MPN is a chronic illness, another set of challenges relate to having to take medications for life. Adjustment is needed to accommodate the treatment regimen, depending on the complexity of the routine, this may be a challenge for some patients. Possible occurrence of side effects is an added source of anxiety.

The out-of-pocket expenditure for treatment is a major challenge for most of the participants especially during the pandemic. In the Philippines, the average cost of medications ranged from P3,000 and P20,000 per month for hydroxyurea and JAK-2 inhibitor, respectively. This financial burden was also noted in other MPN surveys regardless of the country or type of healthcare provisions where the study was done. The direct cost of healthcare including the cost of the medications is a large reason for the financial burden. However, indirect costs such as lost work days and less productivity that was not limited to patients but extends to their caregivers were also important considerations in the overall healthcare cost of MPN.[13,14]

Finally, some nuances observed in Filipino patients with MPN were 1) even though their doctors explained the incurable nature of the illness, the hope of cure was mentioned repeatedly by some of the patients. This hope is anchored to their faith and renewed spirituality. Most Filipinos draw strength from their faith to endure difficult situations and challenges, accordingly 'leaving everything to God' is common and was documented in Filipino patients with breast cancer.[17] While this may aid in pushing for proper treatment among patients, it may be up to the physician to balance expectations with treatment. Hope or "pag-asa" is not always synonymous to "giving hope for cure", doctors should emphasize the importance of hope independent of prognosis and treatment. If hope for cure cannot be given, patients can be directed toward new foci of hope and allow patients to make individual decisions. The balance between hope and realism is vital.[18] A local study of Filipino patients with breast cancer showed that spiritual beliefs, spiritual practices were significantly associated with perceived spiritual well-being. Another nuance is the belief that these diseases are inherited or associated with food, which is commonly observed among Filipinos' perception of disease causation not only in cancer but other disease conditions.[19]

Limitations

A limitation of this study is that, it was done at one point in time. Since the disease is dynamic and chronic progressive, it is also good to look into the symptoms during the differemt course of the disease.

CONCLUSION AND RECOMMENDATIONS

Patients with MPN have heterogenous, co-occurring, and dynamic symptoms. The most common of which were fatigue, bone pain, and abdominal discomfort. Vascular symptoms specifically headache, numbness, and problems in concentration were commonly reported by patients with PV. Fever and weight loss were uncommon. Exacerbation and fluctuation of symptoms were unpredictable affecting their overall productivity both at home and at work. Perceptions about the disease include difficulty in understanding the concept that MPN is a hematologic malignancy. Sources of anxiety/uncertainty include the unpredictability of symptoms occurrence and blood counts, the burden of taking lifetime maintenance medications, the financial burden of living with MPN, and the unpredictability of the disease and complications.

This study provided valuable insights on disease perceptions, sources of anxiety, and coping mechanisms of patients with MPN which can be used in crafting patient education tools that will enable patients and their families to better understand the nature of the disease. A deeper understanding of the symptom experience and disease perceptions of the patients will enhance the physician-patient interaction especially when discussing management options.

It is recommended that the addition of headache be considered in the MPN-SAF TSS questionnaire. Exploring the symptom burden, risk factors, and disease characteristics of secondary MF is also recommended.

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APPENDICES

Appendix 1. Interview Guide Questions for KII

1. How long have you been diagnosed with (specific MPN)?
   Gaano katagal nyo ng napag-alaman na kayo ay may sakit na (specific MPN)?
2. What are the symptoms you experienced and can you expound how severe they are?
   Anu-anu ang mga sintomas na nararamdaman mo? Ipaliwanag kung gaano kalala.
3. From the symptoms that were mentioned in the MPN-SAF TSS, what is the most burdensome for you?
   Sa mga sintomas na nabanggit sa ating MPN-SAF TSS form, anu ang pinaka nagpapahirap sa inyo?
4. Do you have other symptoms other than the one mentioned on the questionnaire?
   May mga ibang sintomas ka ba na nararamdaman bukod sa naka-lista sa questionnaire?
5. Do you have stable symptoms or fluctuating symptom severity?
   Pareho lang ba ang sintomas na nararamdaman nyo or may araw na mas malala ang mga sintomas?
6. Was there change in symptoms now that you are taking maintenance medications compared when you were newly diagnosed?
   May kaibahan ba ang mga sintomas mo ngayon kumpara nung ikaw ay wala pang gamot?
7. How do the symptoms affect your everyday life?
   Anu ang epekto nito sa inyong pang-araw-araw na buhay?
8. What are the factors contributing to your symptoms? Please expound.
   Anu sa tingin mo ang mga bagay na nakaka-apekto ng sintomas ng iyong sakit?
9. What are your expectations regarding your disease or symptoms?
   Anu ang mga ekspektasyon mo patungkol sa iyong sakit o sintomas ng iyong sakit?
10. What are your coping mechanisms in decreasing or trying to alleviate the symptoms? Pls expound.
    Anu ang mga ginagawa mo or iniisip mo para maibsan ang mga sintomas ng iyong sakit?

Appendix 2. Patient Interviews: Additional Quotes

Themes	Quotes
I. Symptom Experience	
Heterogenous and complex symptomatology	***"Mahina ako, nanginginig ang katawan ko. Wala akong lakas para tumayo pa. Madaling mabusog, bloated at pumayat din ako ng husto. Hindi maganda ang pakiramdam ko, akala ko yun na katapusan ko."(PVP4/64/M/ND)*** *"I am weak, my body is shaking. I don't have the strength to even stand up. I had early satiety, I feel bloated, and I also lost a lot of weight. I didn't feel well, I thought it was the end of me."* ***"Noong una ay nagka-stiff neck ako tapos hindi ko maigalaw ang kalahati ng katawan ko na para akong na-stroke. Naduduwal ako at nahihilo. Pinauwi ako mula sa cruise ship at pinasok sa hospital. Na-stroke daw ako. Noong una ay normal ang mga bilang ng dugo, ngunit unti-unting tumaas ang mga platelet at pagkatapos ay pinasuri nila ako para sa JAK-2." (ETP3/44/F/CP) (***"Initially I had stiff neck then I can't move half of my body as if I was paralyzed. I was nauseous and dizzy. I was repatriated back from the cruise ship and was admitted. They said I had stroke. Initially blood counts were normal, but platelets gradually increased a little bit and then they had me tested for JAK-2 and it was positive.)*
Dynamic nature of symptoms	***"Nagkaroon lang ako ng mga sintomas ng pagkapagod at pananakit ng tiyan kelan lang, nung nag-transform na ang sakit ko sabi ng doctor ko. Pabago-bago ang sintomas, hindi ko nalang pinansin dahil mas masama ang pakiramdam ko kapag naiisip ko ito." (MFP6/69/F/CP)*** *("I only had symptoms of fatigue and abdominal pain recently when my disease according to my doctor transformed. Symptoms were fluctuating, I tend to ignore it because I feel worse when I think about it.")* ***"May mga araw na walang sintomas, marami akong nagagawa…pag magaaan ang pakiramdam ko, mas productive ako ng konti sa bahay." (ETP3/44/F/CP)*** *("I've also had periods when I was able to do other things as well. So, there have been periods when I feel better, and I could do a little more in the house.")*
Living and coping with symptoms	***"Sa opisina dati kaya kong mag-multi tasking, madami akong hinahandle, pro nung nagkasakit ako sa dugo hindi ko na magawa. Mas konti na ang workload na inassign ng principal at dineligate nalang sa iba. (PVP1/58/F/CP)*** *("Before I got sick I can multi-task but after diagnosis, because of my symptoms, I cannot accomplish multiple jobs. I was assigned less workload by our principal.")* ***"Lagi akong umaalis ng maaga sa factory para mag undertime dahil sa mga sintomas, madali ako mapagod at masakit ulo gusto ko ipahinga." (PVP5/46/F/CP)*** *("I had to leave the factory early to under-time because of the symptoms, I want to go home and rest.")* ***"I also study myself, I noticed that I have more symptoms when I'm inactive and lying down all day so when I feel the attack of symptoms, I walk around my farm and feel relieved. I also google my disease and symptoms, I feel anxious. After my research I try to live a normal life." (MFP1/72/M/CP) (***"I also study myself, I noticed that I have more symptoms when I'm inactive and lying down all day so when I feel the attack of symptoms I walk around my farm and feel relieved. I also google my disease and symptoms, I feel anxious. After my research I try to live a normal life. ")* ***Nung una talaga akala ko wala na akong pag asa. Pero nung umiinom na ako ng gamot ng maigi nagkaroon na ako ng pag asa. Malakas lang ang pananampalataya ko na gagaling ako. (PVP4)*** *(At first I really thought I had no hope. But when I took the medicine well I had hope. I just have strong faith that I will be healed.)* ***"Lalo akong naging madasalin, nagsisimba ako every day. Nagrorosaryo ako palagi."(ETP4)*** *(I became more devout, I went to church every day. I always pray the rosary.)*

Appendix 2. Patient Interviews: Additional Quotes *(continued)*

Themes	Quotes	
II. Disease Perceptions		
Struggling with the concept of the disease	***“Actually hindi ko naman alam yun kung ano po yun. Ang alam ko lang po, ang concern ko dun tumataas daw po ang blood platelet ko. Kasi baka magkaroon daw ako ng stroke or heart attack yun ang sabi sakin.” (ETP1/68/M/CP)*** *(Actually I don't know what that is. All I know is that my concern is that my blood platelets are rising. Because I might have a stroke or heart attack, that's what I was told.)*	
	“Basta po ang alam ko noon sabi habang buhay ko ng sakit yun. Pero sa akin okey lang, gagaling naman iyan. Iniisip ko noon gagaling din ako sabi ko….pero kung hindi gagaling, mag gagamot na lang ako.” (MFP6/69/F/CP) *(Just what I knew then, doctor said it is a lifetime disease. But for me it's okay, that will work. I thought then I would get better too I said. But if not, then I will just take my maintenance for life.)*	
	“Syempre nag google ako. Ano ba ito? Anong sakit? symptoms mga ganun. Saka wala akong mga pasa-pasa, wala pa ako nun. Sabi ko baka nagkamali, pero dahil nga lagi po akong nagpapacheck up every 3 months, nagpapacheck up ako ng blood. Talagang consistent na tumataas yung blood ko unless mag take ako ng gamot. Si google nagworry din ako kasi cancer of blood yun na nakalagay don.” (ETP3/44/F/CP) *(Of course I googled. What's this? What illness? symptoms are like that. I was confused because I don't have hematomas and bleeding, I don't have any. I thought it might be a mistake, but since I always consult every 3 months, I check on my blood. The blood counts really consistently go up unless I take medicine. I was also worried when internet said, it is cancer of blood.)*	
	“Nung una hindi ko maintindihan hanggang sa nagtanong ako ng nagtanong kay doctora. Kahit nakukulitan na siguro sila, kasi hindi ko maintindihan eh.” (MFP5/68/F/CP) *(At first I didn't understand until I asked the doctor. Even if it's annoying them that I ask many questions, in the long run I was able to understand.)*	
Anxiety and Uncertainty	*Unpredictability of symptom occurrence and blood counts*	***Parang first halos natakot po ako kung anong pwedeng mangyari sa future. Na-trauma ako dahil sa experience ko dati nagsuka ng dugo…kapag sumasakit ang tiyan ko ngayon may fear na maulit pagsuka ko ng dugo. (MFP4)*** *(At first, I was almost afraid of what might happen in the future. I was traumatized because of my previous experience of vomiting blood… when my stomach hurts now there is a fear that I will vomit blood again.)*
	Burden of taking medications for life	***“Hindi ako sanay na may maintenance na gamot. Kaya hirap ako sa pagkakaroon ng gamot na kailangan inumin habang buhay.”(ETP6/48/M/ND)*** *(I'm not used to having maintenance medication. So I struggle with having the medicine to take for life.)*
	Financial burden	***“Hindi na po ako nakakalapit sa NGOs mula po noong nag pandemic. Lalo ngayong parang humina ang company at magbabawas ng tao at may posibilidad na matamaan ako. Yan ang una kong tanong. Paano ang maintenance ko? Medyo nahihirapan ako ngayon dahil may possibility po hanggang May na lang kami. Kaya paano po*** **kung wala na akong hanap buhay.” (ETP2/52/F/CP)** *(I have not been able to approach the NGOs since the pandemic. Especially now it seems like the company I'm working is having financial difficulties. It might soon remove some people. How will I be able to buy my maintenance? I'm having a hard time now because there is a possibility that I might lose my job.)*
	Unpredictability of disease and complications	***“Ang fear ko lang naman kasi yung marinig ko na candidate ako for stroke. Tsaka yung it will lead to something. Yung it might affect yung ibang organs mo kasi it is a blood disorder, hindi na natin makontrol yung blood platelet mo.” (ETP5/65/F/CP)*** *(My only fear is when I hear that I am a candidate for stroke. It might affect your other organs because it is a blood disorder and that they can no longer control my platelets.)*
Acceptance and hope	***“Nung malaman ko na may Essential Thrombocytosis ako, parang okey lang kasi normal lang na magkaroon tayo ng sakit.” (ETP1/68/M/CP)*** *(When I found out that I had Essential Thrombocytosis, it seemed okay because it's normal for us to have a disease when we are getting old.)*	