

Lived experience of the terminally ill individuals

Florance Jeyanthi Sevamalai*

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This qualitative study was done to explore into the lives of terminally ill individuals and how it affected them physically, psychologically, socially and spiritually. A total of six participants were selected for this study *via* purposive and snowball sampling. A qualitative method was used through interviews with six terminally ill individuals. Participants were allowed to express their own experiences after being diagnosed. Thematic analysis was

employed and five main themes were identified which were pain, fear, challenges, coping strategies and purpose and hope. The terminally ill individuals have a great will to move on in life. They find ways and means to fight the challenges in life and find purposes to live. This study shows that terminally ill individuals want to live their lives purposefully and probably face challenges as it comes. Counselors can benefit from this as they can help them find their purpose in life.

Keywords: Counselors; self-awareness; breathlessness; emotionally and socially; ethics review board

INTRODUCTION

Terminal illness is the final or the end stage of a disease where cure is not possible. It cannot be sufficiently treated and is expected to result in the death of the patient within a period of time. Although medical technology has advanced greatly, there will come a time where even the most advanced technology cannot change or reverse a failing body system which results in terminal illness. Terminal illnesses commonly occur in progressive diseases such as cancer or advanced heart diseases or respiratory conditions. In 2016, the three main deaths are caused by cancers (12.61%), heart diseases (22.6%) and respiratory illnesses (21.65%) in Malaysia. These diseases leave the individuals and their family members in devastating situation [1].

Lived experience of terminally ill individuals

A certainty to expect in life is death which is imminent for all. When one is succumbed to death due to disease, one may consider that they have 'lost in battle' and give up on living. When death comes in a sudden form, the victim dies without fulfilling their desires and needs. It leaves the family members to mourn and grief miserably over the sudden loss. On the contrary, a person who knows that he/she are dying, will experience a roller coaster of emotions from the time they are diagnosed with the terminal illness till the time they are approaching their deathbed. Many of these terminally ill individuals' needs and desires are not fulfilled at the end of their life and it seems that helping the terminally ill individuals to meet their needs has become a challenge [2].

Many studies were done with regards to death and dying. These four needs of a dying person which are physical, psychological, social and spiritual. Meeting and addressing these needs may enable the terminally ill person to come in terms with end of life. Understanding their needs and helping them find meaning to their remaining life is an essential role of any care provider. One study conducted on counselors who counsel the terminally ill, found that focusing on their psychological and spiritual aspect reduces the anxiety of death and they are comfortable with themselves and their own beliefs. The theory that addresses the four needs of the dying person is best explained by existentialism. Therefore, focusing on their needs and helping to meet their goals would essentially lead to peaceful and an accepting death [3]. This again means finding some essence in life, which explains why existentialism would be the best approach to understand the terminally ill individuals. The basic dimensions of human situation according to existential approach are:

- The capacity of self-awareness.
- Freedom and responsibility.
- Creating own identity and establishing meaningful relationships.
- Meanings, values and goals in life.
- Anxiety with living condition.
- Awareness of death and nonbeing.

Each one of these dimensions is vital and what makes an individual who they are. This study was expected to meet these basic dimensions. Objective of the study is to explore the lived experience of a terminally ill individual. Central research question of the study is 'What are the lived experiences of terminally ill individuals in the Malaysian context and culture.'

Significance of the study

Many studies were conducted to explore the needs of the dying to enable health care providers to render their care and service. A study, interviewing counselors who have counseled the terminally ill where she identified some of the desires the terminally ill individuals as shared by the counselors. This study will look into obtaining the information from the terminally ill individuals themselves which gives more accurate and specific information about their lived experiences [4]. 15 needs of terminally ill patients that can help healthcare providers to understand better the needs of these dying individuals in the Western context. He had an in-depth exploration of their holistic needs and one of the themes that commonly emerged from it all was self-identity. Patients felt that they lost their self-identity when they were diagnosed with a terminal illness and how they have struggled to maintain who they are amidst the terminal illness. The researcher intends to explore and identify the needs of the dying in the Malaysian context and culture. Furthermore, there is a current lack of local researches conducted to address these needs in Malaysia. Therefore, this study will explore into the world and realm of a terminally ill individual. Understanding them from their point of view, culture and religion, may be able to provide an appropriate guide for care providers to help this vulnerable group [5].

This study is aimed

- Understanding an in-depth holistic need of terminally ill individuals in Malaysia.
- Exploring and obtaining some insights on the emotions and thoughts as they are approaching their death with regards to family/loved ones.

Department of Psychology, HELP University, Lumpur, Malaysia

Correspondence: Florance Jeyanthi Sevamalai, Department of Psychology, HELP University, Lumpur, Malaysia, E-mail: florance.jeyanthi@ramsaysimedarbyhealth.com

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- How it can facilitate in preparing counselors to understand the needs and emotions of a terminally ill patients and able to use the appropriate modality to address patients and their families according to their own culture and religion.

This study is significant because it will explore the needs of terminally ill individuals in Malaysia with a diversity of race, religion and culture. Understanding patients from their view point at their most testing period of life and taking into consideration their races, religions, cultures and beliefs are very important. A counselor should be able to factor all these in relation to their emotional, psychological, physical, social and spiritual state. Their needs at this point of life may determine their meaning and purpose in life. Therefore, exploring in various aspect of their life may help them find meaning in life. Finding meaning in life allows the acceptance of their fate which subsequently leads to a peaceful death. This study will look into the physical, emotional, social and spiritual needs of the dying person. Literatures have stated that these are the basic needs of a dying patient that need attention [6].

In social constructivism, it is believed that every individual seeks to understand the world in which they work and live in. They create meanings out of their experience which are unique to them, although others may have gone through the exact same experience. Therefore, meanings are a constructed through the experience they go through. This framework was adopted because it allows the researcher to explore and understand the lived experience of the terminally ill from their view point.

METHODOLOGY

Design

This study was done in a qualitative manner. Qualitative study allows a descriptive picture about the experience of a terminally ill individuals. Qualitative research as “an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem.” In line with this, transcendental phenomenology approach was employed as the information collected was formed based on the description of experiences from the participants. Transcendental phenomenology approach is an appropriate method since the study involves the lived experiences of terminally ill individuals as being told by them and no interpretation done from the researcher. This method exclusively addressed the study of experiences from the participants’ point of view, therefore, no hypothesis or predetermined notions were outlined. Phenomenological design allows a deep and meaningful description of the subject. Rich and factual information was required to explore in depth the needs of the terminally ill [7].

Participants

Criterion for participation is individuals with any type of terminal illness from the age of 35-60 years old. According to Erik Erikson developmental theory, ages between 35-60 years old are at the 6th and 7th stages of life where intimacy versus isolation and generativity vs stagnation takes place. At this stage of development, an individual is settled in life in terms of relationship (the reason for age of 35) and career; they have probably established a sense of commitment, safety, care within a relationship, feelings of usefulness and accomplishment in life. Hence exploring their reaction from every aspect, when they are physically and mentally incapacitated at those stages of life is the essence of this study [8].

Three Malaysian males and three Malaysian females participated in this study. They were of Chinese and Indian ethnicities and spoke in English. This was to explore the needs, emotions and thoughts of the different races in Malaysia. A total of six participants were chosen to carry out the study as this is the minimum acceptable number of participants required for a qualitative study. Purposive sampling was done through the church contacts and snowball sampling through the contacts provided by the church. All participants were explained about the study and its benefits through an informed consent.

Participants were also reminded that they can withdraw themselves from taking part in the study at any time they choose to. An informed consent was obtained prior to the interview. They were assured of confidentiality and data protection and that all audio recorded information will be deleted after the study. All participants are called by a pseudonym and their actual names are kept confidential during the analysis phase. Simple demographic information was obtained when the participant agrees to participate.

Ethical consideration

Qualitative research has contributed greatly in recognizing the need for knowledge in the end of life care. Due to lack of familiarity, the ethic committee tends to make decisions based on criteria designed for experimental research which is inappropriate. The benefits of the study among the terminally ill individuals is found to be more than the potential risks incurred, therefore one should look at the positive aspects that it yields the participants welcome the idea of sharing their life story. Eventually, Ethics committee review the policies which are based on clinical trials, take into consideration the unique attributions of qualitative methods [9].

It was necessary to show that the study has ethical values of beneficence, justice, and respect to the subjects prior to recruiting the participants. All participants will remain anonymous and confidentiality was observed on all data during the analysis process. Pseudonyms were given to each participant, so no responses or demographic information could provide any identification in the data protected confidentiality.

The proposal of this study was reviewed through and approved by the Ethics Review Board (ERB) prior to commencement of the study [10].

Data collection

The goal of the study is to explore the holistic needs of a terminally ill patient. A face to face interview was done with each of the six participants. It was an open interview where participants were allowed to express themselves freely. Open interviews enable participant to share their perspective of their condition rather freely than be limited by structured questions. However, the researcher had used a set of guide questions as prompter to ask further when the participant does not know what to talk about. The guide questions were also used to check if the participants have shared and covered their experiences in terms of their physical, emotional, social and spiritual aspects. They were allowed to speak freely which explored the areas of their minds, their experiences and journey and what is meaningful to them. The researcher wanted data that structured the story of the participants rather than guiding the participant to provide the data that the researcher wants. The consent has clearly described about the study to the participants and to start of the interview. As the interview progressed the researcher prompted the participant with questions for further discussion based on the information provided by the participant [11]. A licensed Counselor was consulted and requested to be available during the interviews to step in if the participants broke down or becomes emotionally overwhelmed. All interviews went well and smoothly and did not require the intervention of a counselor.

Each interview was conducted for an about 30 to 45 minutes at their place of convenience. Some participants had a lot to share; therefore the interview was extended for more than 60 minutes. An informed consent that stated the reason and the benefits of this research was obtained from all participants prior to the interview. The consent also stated regarding obtaining permission of the participant to audio record the whole session. The recorded sessions were only used for transcribe verbatim after which will be deleted. The transcriptions were sent to the participants via electronic mail for check of accuracy of information [12].

Data analysis

The collected data was transcribed verbatim. The data was reviewed through these stages of thematic analysis

- Transcribing.
- Delineation process.

- Initial coding.
- Focused coding.
- Thematic coding.
- Validity check.
- Modifying themes.
- Contextualization of themes.

In the transcribing phase, all recorded data was transcribed and read through. In delineation process every word, phrase and sentences that expressed the important meaning was highlighted. With this the initial coding was developed where relevant and important actions, feelings and thoughts were labeled. This included any information that is repeated by participants, explicit statements, surprising statements or information that was mentioned in other studies or journals. At the focused coding phase, the themes were filtered further for new codes where redundant codes were dropped and relevant ones were kept. This is also called category development. Moving on to thematic coding, clusters of meanings was developed from the categories and a distinct theme was constructed from the cluster of themes [13]. This was followed by validity check where each participant’s interview was summarized and checked with the respective individual for accuracy of data and meaning. After the validity check, the whole data was re-examined for modification or addition of themes if new significant information emerged. With this, the final themes are placed back to the overall context where it emerged from.

Data modification

Since there was no discrepancy found in the collected data during validity check, the researcher finalized the themes.

RESULTS

The findings obtained were in consistent with the research question which is ‘What are the lived experiences of terminally ill individuals in the Malaysian context and culture.’ The literature reviews suggest that a terminally ill individual has to be cared for holistically. Exploring and identifying their needs physically, emotionally, socially, psychologically and spiritually was the core of this study. Therefore, based on these factors, the findings will be discussed here. Five main themes were identified after a thorough analysis as described in the methodology chapter (Table 1).

Table 1: Thematic table.

1st main theme: Living with pain			
Physical pain		Emotional pain	
2nd main theme: Underlying fear			
Fear of the known		Fear of the unknown.	
3rd main Theme: Facing challenges			
Negative thoughts, behaviour and emotions	Financial constraints	Affected body image due to illness	Physical manifestation of symptom
4th Main theme: Embracing life with positive changes-(coping strategies)			
Family as a support system	Spiritual beliefs	Affirming actions	Coping with treatment
5th Main theme: Hopes and purpose in life			
Inspired to live	Finding fulfilment	Living for family	

Before the themes are discussed, it is important to know the background information about the six participants as the contents of the interview has specific situation or history.

Participant 1: 60 years old Chinese female. She is diagnosed with breast cancer and spread to the liver and lungs. She is a widow who lives with her sister and sister’s family and currently not employed. She is undergoing chemotherapy [14].

Participant 2: 53 years old Indian female who is diagnosed with breast cancer. She had her breast lumps removed and went through chemotherapy. She is a single mother and currently works as a security guard.

Participant 3: 35 year’s old female diagnosed with breast cancer and has spread to the liver and bones. She is still single and currently unemployed. She had gone through chemotherapy once and currently going through another round of chemotherapy due to the spread to liver and bones.

Participant 4: 60 years old Indian man diagnosed with lung and heart failure. Regularly hospitalized for shortness of breath and abnormal heart rhythms. He is married and has one child. He is unemployed and depends on his pension to support his family. His child is a mentally challenged.

Participant 5: 36 years old Indian man diagnosed with Bruton’s Disease (Primary immunodeficiency disease). He is single and does part time teaching. Has to go for regular infusion of medication to keep him alive.

Participant 6: 35 years old Chinese man who is diagnosed with cancer of the colon and had spread to the lungs and bones. He is undergoing chemotherapy. He is single and unemployed [15].

In sharing of their experiences, these are the five themes that emerged as topics of concern to the participant’s pain, fear, challenges, coping strategies, hopes and purposes.

Living with pain

Pain is a common feeling that all participants experienced. Living with pain is an ordeal that they have to deal with on a daily basis. Interestingly a majority of them had similar type of pain. The researcher had categorized their pain into physical pain and emotional pain.

Physical pain

Physical pain refers to any kind of pain that is felt in the body due to pathological or mechanical impact. Almost all of them experienced pain at some point in the course of their illness.

Participant 1: After four months, I had pain, So I went to see Prof Yip la. She said no good. Pain ah! When I wake up in the morning, I pain ah! When the pain come aaiyoh ma! Very pain oh. Pain here, pain here, pain here.

Participant 2: They would infuse antibiotic, when I receive the antibiotic, it was so painful that I felt like I died, when I have the infusion, I would ask the nurses to massage my hand [16].

Participant 3: And this time around I didn’t want to go through chemo anymore because i know the pain and the torture that I have to go through but the only reason why I agreed to it was because that was the only option my doctor gave me .Ya ya it is very painful. Ya the pain and then I can’t stand too long, I can’t sit too long.

Participant 5: Because I have been through the extreme pain of pain, until they send me to a psychiatrist.

Participant 6: Because previously ah, I can’t even I can’t even wakeup myself because my shoulder pain is very pain the pain are the terrible one.

Emotional pain

Emotional pain is another type of pain experienced by these individuals. All of the participants experienced some emotional upheavals during the course of their illness.

Participant 1: Cry every night

Participant 2: Ya, so I never tell them about my pain and misery. But my brothers, I am not sure why they are like this. I have four brothers and none are bothered about me.

Participant 3: Because like watching them watch me suffer was worst thing any child would go through right. Ah! I had that feeling. I had that 'oh! I rather die' rather than going through this.

Participant 4: Then I said, suicide is out of the mind. As you grow older, you got nobody to help you; it's a painful life you know [17].

Participant 5: Three times it came so three times I had to resign as well. Actually, I was going through some kind of depression too.

Participant 6: Cannot go for any work la. So, because I just started work, previously but suddenly you cannot work. You got nothing to do la. Feel very sad la. You can't do anything; you need help for everything, just helpless.

Family disputes, sufferings families go through, suffering the participants go through and lack of family support have caused emotional pain to some and for them it is probably far more painful than any other pain. Physical pain can affect the quality of one's life and subsequently contribute to the significant suffering. Pain is perceived uniquely by each individual and other negative factor such as family conflicts, lack of family support and financial worries can affect the overall sense of suffering [18].

Underlying fear

There are many fears a terminally ill person go through during their course of illnesses. They all have uncertainties in life. They have underlying fears of things that they know and things they do not know that might happen during their course of illness. These are the few fears that the participants have shared that signify the impact of the illness in their life.

Fear of the known

Upon being diagnosed, the participants become aware of their diseases. Knowing about the disease and consequences or the side effects of treatment and the pain they have to go through bring fear in them. Most of them verbalized their fear, knowing what will happen to them and that it is going to be unpleasant.

Participant 1: First thing, going to die. Ya la because I know cancer very pain one ah! Also got scared la. Half half la. So, I think I am already old, 60 mah!.

Participant 2: I requested to the doctor not to inform me of the results because I don't have the courage to accept it but they said they have to inform me. I insisted that they inform my niece but they persistently told that I have to know.

Participant 3: I never got over the whole needle phobia.

Participant 4: I was praying that nothing must happen, nothing must happen. I've got a long way to go some more. You know I have to do this and do that. I asked him (doctor) how is it. He replied it doesn't look good but we'll wait for the specialist.

Participant 5: How to say scared in a way. Scared that I need to not to die. But I can't stand the suffering, the pain you prick 10 times it was ok but now I can't stand it anymore. Even for one needle, I will question them like 'why do you want to prick me?'. That kind that kind of scare that kind of pain, that kind of pain, the fear of pain.

Fear of the unknown

Fear of the unknown equally affects these individuals. The fact that they do not know what is going to happen to themselves are some uncertainties in life.

Participant 1: Now ah! When you wake up, when you sleep afternoon, daytime or night time, when you suddenly wake up, you suddenly feel scared. Don't know why.

Participant 2: If I die, what's going to happen to my son (sobbing). If I am told that I have another cancer, I will never be able to accept. I am not sure if I will live or if I will go mad, I don't know.

Participant 3: Ya the chemo is the worst I would say. It's not even the cancer that I fear but it's the chemo. The treatment. Ya a lot of side effects, a lot of aahhh ...weird things that happen to your body which you can't even explain. But you just have to go through it I guess.

Participant 4: I said I will be alright la but, in my heart, I've got my fear la you know. Have to take it la, no choice, you are already suffering.

Participant 5: Sometimes it snaps. Where you get very lonely. I can't do much in this. I can't do anything. Dare not do anything. Just take medication and sit around and do nothing. That's the best. I, don't go out, I don't drive because in that situation if I drive I know I will be doing something else [19]. Each one of them has different fears but whatever their fears are, they have to learn to face it.

Facing challenges

The numerous challenges the participants face, seem to be the bulk of the findings. The challenges were grouped into focused themes which were Negative thoughts, behaviors and emotions, financial constraints, altered body image and physical manifestation of symptoms. Living with these challenges were the most difficult thing that they have to endure and live with.

Negative thoughts

The moment one is told that they have a terminal illness, negativity sets in spontaneously and it manifests in one's thoughts, behavior and emotions.

Participant 1: Die la. Say I want to die. Feel like dying. But when I in pain, I feel I wanna die.

Participant 2: Ya my sister passed away, next they thought I will pass away. I know when I will die. I will die in five years' time. (Crying) I know that doctors are lying. I know, I have not done anything to anybody, why should I go through all these (crying).

Participant 3: I had the whole question why? Why me? The first time around I was angry at God. I was like why you know like I am so happy and then you give me this... why?

Participant 4: So really Aah! sometimes I will sit down and tell myself 'what am I doing in this house ah. What is the use I am living this type of a life. I am not gaining anything out of it. I have no happiness at all. Nobody to sit with me and laugh with me you know. Nothing is important. My mind is idle like, you know.

Participant 5: Sometimes you are tired but sometimes you can't do anything. Because it is quite difficult it's quite difficult to deal these kinds of things, because you see once you go back then you'll see all friends. Most of them in Kota Bharu are doing their own business Oh yes. I have questioned God many times. No did not get an answer till today.

Participant 6: I just lie in bed thinking I am dead. I wanted to faster go and pass away. Early stage I was angry with God. I feel not fair. Why is me?

Negative behavior

Thoughts and actions are related to each other. Negative thoughts would convert to actions that can cause undesirable results.

Participant 1: Ya I don't want to eat don't want to see anybody. I always believe the doctor. After operation, have injection ah! chemo, after every time come back ah no appetite to eat, no mood, all the time sleeping, don't want to come out, saying want to die, die.

Participant 4: And that alone I was planning for nearly a week. How am I going kill myself, if I kill myself with a knife, it will be very painful, I can ride my motorbike fast and bang into something, if I die off, never mind, if I end up with broken bones, I am going to suffer more. What am I going to do? Drink acid, it will burn. All sort of things came. Finally, all tablets, antibiotics, old antibiotics, that also God doesn't want me to go.

Participant 5: Ya. 3 times I tried to commit suicide. When I was 14, 16.

Participant 6: In the beginning, you want to kill yourself until I wanted to pull the plug and give up everything. Most of the times I also don't know what happen? I am in my own room, my bedroom so I don't know.

Negative emotions

Participant 1: Cry every night Last time come back sleep, come back sleep. When starting chemo, they message to you, cannot eat other medicine. So, I follow la, then after that also got in the lungs here and there (spread). So how?

Participant 2: You (referring to GOD) gave me husband and you took him away, you gave me a child and I didn't get to raise him, I don't have a house, I feel as if I am living like an orphan. I want my brothers to be closely bonded and love me. I want my sisters in law to be close to me but they are not.

Participant 3: But when the second time around I kinda was disappointed because I took all the precautions, I did whatever the doctors told me to do, I took all the medication, so when it came back, it was more like why did it come back, how did it come back, what did I do wrong, those questions were like psychologically affecting, and brings you down [20].

Participant 4: What's the point I am living also. I want something I don't get. And all my money, she (wife) came with nothing. It's my entire house, my money'. She is waiting for me to die to enjoy all those things. Why am I suffering, waiting for the thing to happen?

Participant 5: Three times it (Seizures) came, so three times I had to resign as well. Actually, I was going through some kind of depression too. Sometimes you are tired but sometimes you can't do anything.

Participant 6: Yes. So depressed that time. My life just went upside down when I found out because the company cut my salary. Cannot go for any work la. So, because I just started work, previously but suddenly you cannot work. You got nothing to do la. Feel very sad la. You can't do anything; you need help for everything, just helpless.

Financial constraints

For some the financial support was a concern. While some of them had to be dependent on family members to help, there were others who work and still support their families. Their main worries were the fact that they believe they are a burden to their family.

Participant 2: I must somehow buy a house you know how many times my brother has asked me to leave the house. He has told me to take my son (son is growing up in brother's house) and get out of his house and if anything happens to me, who is going to look after him. Even if I die, I want to be with my son, I want to be his shadow and take care of him. I have my EPF savings, I also have medical insurance, and I am paying monthly. Nobody can help me so I have to work for that.

Participant 3: I need to, my parents need to (laugh) we need to invest on a good bed. So it's like a back friendly, you know like the chiropractic. , I mean, we are not like having financial difficulty or anything but you know those beds can cost a bomb and my parents are getting older. Treatments in private hospitals are really expensive. I mean I did tell them that I think I need to change at least one of the beds so that I can sleep a bit comfortable but I don't really push them right.

Participant 4: I am sick also I do everything for them, I do everything for them, despite like that, I am living on pension. I let them go for shopping. I take out my savings for Christmas shopping. I make sure the tree is decorated. No doubt I am suffering, I am sick, so they are not affected in any way. What they need I am fulfilling as a father. I am doing everything although I am suffering.

Participant 6: So I went to Perkeso. Next week I am going for interview. See got the chance to get a bit of money. Otherwise very troublesome. Then financial is the biggest problem. I need to buy juice, I need to buy milk. I need to drink the very nutritious ya. So luckily my parents got a bit of pension, can still support me la. For a long term aaahhh... not a solution la for me.

Altered body image

Five of them experienced some changes in body image. Some of the changes have affected them in some ways such as feeling of embarrassment.

Participant 1: See all black one; see (showing her fingers). But is ok now, seeing.... But see dark dark one. Dr also said chemo. Last time people say face also got ah black black mark. So skinny you see. 14 kg oh!

Participant 2: I was 75 kg and after the kidney surgery I came down to 45kg... just within 2 months.

Participant 3: Although I also prayed 'please don't let my hair drop but that's impossible because that's going to happen.

Participant 5: I have been taking antibiotic since I was young. That why, you see my teeth. It's different in colour.

Participant 6: I don't like it ah. It (colostomy) is very troublesome. The stoma bag bothers me. I am waiting hopefully for the surgery. Sometimes walking then suddenly 'brurr..brurr'. very loud.

Because the smell is unpleasant. So, when I go out I also don't dare to clean. This is stopping me from doing things. Because it cannot be controlled. Sometime when I eating with friends, it just 'brur brur aiyoh! It's very embarrassing!

Physical manifestation of symptoms

This is one of biggest challenges they face due to the side effects of treatment and as a result of the disease itself. Some find it torturous but accept it as they do not have any choice.

Participant 1: Very tired so, like this la yesterday, chemo la, you tired two or three days. Like this today also very tired, must lie down. Ah the 1st, 3rd chemo. After I cannot eat, cannot what, take pills la. 2 weeks pills, after that injection.

Participant 2: Ye I stopped work because I had leg swelling.

Participant 3: Ya that happen and also diarrhea but nausea is the worst of it all. And losing the appetite. The constant vomiting is the annoying part because you are constantly vomiting and there no stop and its constant. Like 3, 4 days straight so it was like. I didn't like that.

Participant 4: I don't know why. I went to the bathroom, I uri Participant 4d, after uri Participant 4 suddenly like very bright, you know. Like you in heaven like, very bright. Then after that I can hear 'papa, papa fell down. Papa fell down'. You see at this stage in this old age ah, something is happening to you. You won't know what is happening. It can be the heart, can be the pressure too high also. A lot of things la, our body can create a lot of things. We don't know and it's very dangerous.

Participant 5: My epilepsy will last around 5 hours so with all these they have to intubate me. Lung infection because due to too many times of intubation. What happened was I couldn't walk all of a sudden, first the knees started to swell, pain. First left leg then the right leg. And then it slowly became very weak and I was unable to walk.

Participant 6: Yes, wow very terrible. We keep vomiting and diarrhoea. You can't control one. Then diarrhea, can't control. You want to vomit, just suddenly can vomit. I can't work because I am too weak la.

Every time I work 2, 3pm I will breakdown already la. Then some more after the chemo, the whole week is so weak, then got vomit, Then....then you got, you can't do anything la. Even I walk, I want to go shopping, I just walk too short already. Then I knock out already, and then I have to sit an hour to rest. I can't do anything la basically because morning I try to jog, then I can't run fast because my bone is hurting la. Then very weak la myself.

Embracing life with positive outlook/changes

All of the participants developed some coping mechanism/strategies to live on. It came in the form of family, God, positivity and treatment.

Family as support system

Family played very important role in most of the participants' lives. They have attributed their 'living' to their families. While most of them are grateful and appreciative of their families, two of them did not have the support and had to find other factors to hold on to.

Participant 1: Ya ya family very support me. My sister's son and daughter all very love me.

Participant 2: But it's actually my parents that actually made me feel strong. Sometimes my family doesn't especially my mom, so overly caring, and she has like separate food 'oh no no this is Participant 3's food'.

Participant 5: Because I have that kind of family, that's why I am sitting here. Otherwise I will be somewhere else. First my mom. She was there 24 hours taking care of me. Then my family she couldn't work because of me. It is my own motivation to walk. I can't even stand. My father was supportive.

Participant 6: Then they have to, early morning have to cook some healthy food. So, I cannot eat the normal food, so they specially make one for me. Then they need to bring me to toilet. Sometimes have to take care of me. They also find solution, Chinese medicine. Without them I also cannot survive so long.

Spiritual beliefs

All the participants except for one believe in God/ Creator and have trusted and surrendered their fates to Him. They also believe that there is a reason for all they are going through and some even think that is a kind of blessing.

Participant 1: I use to think, why this happening to me is. Looks like God loves me a lot (while laughing). He is trying to take me up fast.

Participant 3: I didn't have any nausea, I think I am quite a religious person so when I was diagnosed, I actually really prayed to God to help me throughout the whole chemotherapy. And the one thing I actually asked God was 'please don't give me nausea' although I also prayed 'please don't let my hair drop but that's impossible because that's going to happen. ok..so, there is a little bit of light at the end of the tunnel which God is actually showing because like certain things doctors and doctors and family members can't give and can't do so much but God can. Ah! so for me was like those little little things that God had shown me strengthen my believe in God.

Participant 4: For me, you got one life and when you go up there, you have to answer why you came up. He is telling 'I (God) am with you, do it'. This means that God is with me and he knows the trouble I am going through. And He is telling 'you bear the cross for me'. 100% I depend on God. He wants me to go through certain stages till His will is done.

Participant 5: Then its God. Without him I don't think I could have made it. Because certain things change. What I didn't ask, I get. It was blessing from God.

Participant 6: It is my religion because I believe in creator, our creator will bless us, so I try to stay positive all the time. Thankful to my creator because I think no people can experience this very young stage. Ya it's good for me at young stage, I can still fight back the cancer.

Affirming actions and thoughts

Being positive was one the biggest coping strategy that all participants develop. They develop it after enduring much pain and sufferings. The experience they went through helped them to grow in maturity and acceptance. They all believe that being positive is very important to stay alive and to face the future of their health.

Participant 1: Don't think too much oh! So, you don't think when you wake, you are happy la. Think happy one la. Don't think sad one la Don't know. I believe in myself. You see the entire garden, I do. If I go outside, I see a lot of people, then I will have positive thinking. If sitting at home, only inside the room, nobody can see me.

Participant 1: I feel I can do more than this. I can live. I have a lot of things to buy. I feel I can survive. I don't like to talk to cancer patients because they always talk about the same thing, negative stuff. If they talk to me I will tell them not to talk about negativity. I want to live. They would frighten me but I want to live.

Participant 3: So, I didn't want, what happen for me or for a lot of other people out there who are going through this, so that's why I started the whole Instagram platform, where I share my story and tell them, just because you have these setbacks in life, you don't have to put your dreams at a pause. My purpose on Instagram is not to meet new people, I mean meet guys and go on date. It is to meet new people and understand what they going through and allow them to convey whatever they want to say to me or to speak to somebody where they cannot like to whom they cannot talk to like family members.

Participant 4: So, you must never give up. I am different kind of a person. I fight against problems.

Participant 5: To help and support my kind of people, who are suffering like me. My family and my dreams. I have to take care of my family. I have a sister too (Motivating factors).

Participant 6: Then she gave me book to read and see more books on how other people are fighting for their lives. Then I start to read books and write down my journey. My cancer fighting journey.

Treatment as a coping mechanism

Treatment in the form of medication or supplement was life saving for some. They felt better and seemed optimistic after receiving treatment. Some did not mind the side effects because they felt and saw hope.

Participant 1: I believe in Usana (supplement). Usana is from my sister. I feel Usana can help a lot of people. I can eat. Got strength to do house work. Last time come back sleep, come back sleep.

Participant 7: Now I know why people stop chemotherapy, why people don't want chemotherapy. Because it really it takes a toll on your body and it's not just that particular time that you are going through chemo, it is going to affect your body for the rest of your life. Your body is just damaged, that's it. But, I mean at the end of the day, it's still helping you to kill off the cancer cells. And in a good way, we look at it in a positive way, that it's just helping you.

Participant 5: I'll die. (Laughing). I get infection if I don't get it (treatment). It's weird!

Participant 6: After the 1st chemo, even the side effect is very terrible, vomit ah, nauseous ah, then tired ah but the feedback (outcome) is good ah. So, I feel less pain, my back pain also very less, become lesser. After the 2nd also better already. So, this is the 3rd la. So, the 3rd I hope is getting more and more after the 2nd one, I can even go for morning jog.

Finding hopes and purposes to continue living

Hopes and purposes are the reasons for one to continue to live. Therefore, all participants have found something to be hopeful about and a purpose to continue living without giving up. All of them wanted to live and had the will to live.

Inspired to live: Holding unto hope.

All participants are inspired to live. They gain inspiration by holding unto hope and finding fulfilment.

Participant 1: No, I feel still got chance, positive thinking. Don't know. I believe in myself. All bad things, don't want to think. Think of positive things

Participant 1: I want to live till 80 years old. I need to work. I have to live for my son. I have to fulfil my desires.

Participant 3: I guess it's just, I wouldn't say hope, but I would say believe, it's not the hope that I am going to do all these things, it they believe that I have that I can live a long life. People have lived with stage 4 cancer and

then cured from it and lived for like 20 over years as well. And there are people who have been diagnosed and lived only 2 months. So you see we can't really say, so I just believe that I am the few who will live for the next 20, 30, 40 years. So I believe that.

Participant 4: So, I said I am not going to give up. I know something is happening to me, I don't want to die on this floor

Participant 5: To be strong and not give up. How to be strong, I don't know but I have to be strong.

Participant 6: After the chemo. I feel very positive; I think I can do it. Improve oh! I feel happy after the chemo. Then I feel got improvement. I see the result is getting better and better, I see hope.

Finding fulfillment

The participants have found activities that keep them 'alive'. There are various things they do that keep them going and some think that it is their purpose.

Participant 1: Now I can go to getting alone for one week. Go here, go there walk and walk. You see the entire garden, I do.

Participant 1: You know what, I just need a house, nothing else then I will be very happy. I don't have anyone. But I have to somehow buy house. I am hopeful about that. I don't have the money but I have to buy a house for my son's sake.

Participant 3: And this time around 'be inspired to inspire'. When I get messages from people that are so moved by this whole process, it gives me more positivity. So, it's helping me in a way. Parents and sisters they are very fragile and anything you say hurts them. So, I allow these people to come to me and talk to me if they want to talk to me Ya! and knowing that another person is being inspired... that happiness actuallyyou can't put a price. That happiness it gives me, you can't put a price.

Participant 4: I will do all the cleaning in my house

Participant 5: I teach English I give house tuition. I have also recently finished my degree. The reason I took my degree also because I don't want my brains to freeze. My dream is to pursue my studies. To help and support my kind of people, who are suffering like me, to help them to go through I have a dream to finish my doctorate so that I die with that.

Participant 6: I play games to try to entertain myself la. I even go see movies,

Living for family

Some of them find that family is their reason for their survival, therefore they have an obligation to live for them.

Participant 1: Ya! sister ask to come back, stay here.

Participant 1: but now my only worry is about my son. How can I leave him? I want to help my sister as much as I can. I want to also give my brother and sister-in-law. I use to take care of my sister who had cancer. I have seen her suffering and I was there to care for her.

Participant 3: So, when my mom always had this dream to open up her own catering, I was like why not. I helped her out you know I was like... ok I will help open up, open it up for her. Touch wood, I mean it's going fairly well.

Participant 4: I've got a long way to go some more. You know I have to do this and do that for son.

Participant 5: My family and my dreams. I have to take care of my family. I have a sister too.

Obligation to family plays an important role for these participants. They feel that they have to live for family.

DISCUSSION

This study was intended to explore the lived experience of terminally ill individuals and how they were affected holistically, physically, psychologically, socially and spiritually. A few studies have stated that these are the main areas of concern for any terminally ill individuals and addressing the needs in these areas may lead to better acceptance of their situation. The findings obtained from this study are in consistent with the main areas that were meant to explore. Although they were named under different themes, they all fall into one of the four aspects which are physical, psychological, social and spiritual.

Following the interviews and analysis, these five themes were identified

- Living with pain.
- Underlying fear.
- Facing the challenges.
- Coping strategies.
- Finding hope and purpose to continue living.

These five themes seem to have covered the holistic being of each participant in the aspects the study was meant to cover. Each theme had sub headings that were related to the main theme. Pain was shared and described in two ways which were physical and emotional pain. These are part of physical and psychological aspect. Fear came in many forms, so it was deducted to as known and unknown fear which was able to encompass all the fears that were shared. The fears faced by the participants are something to be looked into and addressed psychologically. Fears and worries about what will happen or fear of the unknown among his participants and how will it affect their quality of life and attaining their personal goals. Fear affects the cognition and emotions of a person if it is not helped as some of them cried not knowing what to do about the fear during the interview. The challenges that the participants go through during the course of their illnesses are tremendous. There are different facets of challenges which range from negativity thoughts, behavior, emotion, to financial burden, altered body image, physical manifestations of symptoms. Every one of them is linked as one can lead to the other. The challenges are biggest hurdle that the participants endure and unlikely to avoid. Psychological problem can cause emotional distress, however these can be curbed through social support if the physical issues are resolved. Overtime the participants developed strategies to cope with their situation. Family support, spiritual support, positive thoughts and action and treatments were some ways the participants found comfort. One study that can substantiate this finding state that psychological and spiritual support can reduce anxiety of death. They were all very motivated to live and had reasons, hopes to continue living. Some hold unto to hope and find fulfillment in life while some felt that they have to live for their families. Finding meaning in something to do or achieve have become their objective to continue living.

The six participants have shared their upheavals and ways to cope with it which are the core aspect of this study and the findings were consistent with all the participants' responses. The interesting part of this study was that none of the participants shared much about dying. They spoke mostly about surviving through positive outlook/ changes in life. Most of the previous literatures did not mention much about surviving and fighting terminal illness. Despite the challenges they go through in life, these participants want to live.

Pain was one the common issues faced by the participants, where it indirectly has caused fear in some. The source of pain was from the disease itself or due to mechanical sources such as needles. Needle have caused phobia in some. Being 'pain free' is one the goals of keeping the terminally ill as comfortable as possible. 100% of participants in her study have mentioned that it is important that they are free of pain during their course of illness. In another study, pain was viewed as most feared by terminally ill patient and a survey revealed that 'freedom from pain' was ranked the highest need in end of life care. Pain is perceived differently by each individual and untreated pain causes more misery than other issues such as sleep deprivation, nausea, vomiting and lethargic. Emotional pain is another type of pain suffered by some of the participants. Emotional pain will also enhance the misery of physical pain. Patients who suffer from

emotional pain are unlikely to find peace and comfort. Living with pain is one of the major issues that was shared as it has affected them the most compared to other challenges hence this was chosen to be a theme although it is also one of the many challenges they face. Pain is one of the most excruciating experience that the terminally ill face. The participants in another study stated that all they wanted is to be pain free during the dying moment.

While pain affects physically, the emotional pain affects the person psychologically. 'Anxiety as a condition of living' as one of the existential approaches in the basic dimensions of human situation. He explained that such anxiety arises when a person confronts pain and suffering among other situations. In defining existential suffering, he explained about total pain which encompasses physical, psychological, social and spiritual pain. He stated that physical pain can be exacerbated by emotional pain.

Fear was something most of the participants experienced. There were fears that they are aware of and fears about things they are not sure about. Whatever type of fear faced, it was a bothersome because they shared and verbalized their fears. Fear affects one's psychology and subsequently affects their thoughts and behavior such as one participant has fear of needle which has affected him so much that he would not allow the nurses to prick him. Fear and worry as one of his themes and how fear has impacted the lives of the participants. Fear of leaving behind loved ones, fear of painful procedures, fear of carrying out routine tasks were causing a lot of anxiety were the identified fears in the participants in this study. The fear of quality of life, fear of discovering something new, fear of new side effects, fear of leaving responsibility were the unknown fears that experienced by the participants. One study about counselors who counsel terminally ill, mentions that fear is one of the emotions that they experience and states that the terminally ill may not be able to achieve state of comfort when they fear loneliness; isolation and leaving loved ones behind. In this study, counselors shared that their clients feared suffering and pain and also the dying process. The interesting fact about fear among the participants in this study was none of them verbalized that they fear death or dying. It seems death or dying was not something they wanted to discuss about. In existentialism, death is not viewed as a bad thing but as part of basic human condition. The participants have probably assumed that if it happens, it will happen.

Challenges faced by these participants were the major issues as several different aspects of their lives were affected. Negative thoughts, emotions and behavior have caused a lot of anxiety in them. Other challenges that may have directly or indirectly contributed to the negativity are financial burden, physical manifestation of symptoms and altered body image. Initial thoughts that come into their minds when they are diagnosed is that 'I am going to die', 'I can't live like this', 'No point in living', 'why me, I have not done anything (questioning God)' and followed by negative emotions where they go through feeling of depression, frustration, disappointment and hopelessness. This leads to negative behavior such as isolating them, attempting suicide and loss of interest in life. This is a very typical cognitive behavior changes where distressing emotions results in maladaptive thoughts which can change behavior. 45% of terminally ill may end up with some kind of depression that is linked to suicidal thoughts.

Emotional, social and financial anguish can be more distressing than the physical suffering. They suffer several dilemmas such as isolation, fear, anxiety, burden to family, low self-esteem, financial constraints and spiritual dilemma which are in consistent with challenges faced by the participants in this study. The physical manifestation of symptoms is tormenting to live with where it is caused by side effects of treatment or by the disease itself. Lethargy, nausea, vomiting, diarrhea, some experience epilepsy among other symptoms that have taken a toll on their daily living. Participants in study had decreased level of activity and found themselves at the lowest point of life during this phase.

The physical symptoms have taken a toll on their activity of daily living. Financial burden seems to be a challenge for some of them. It is either about cost of treatment or about what is left for the family after they are gone. Treatment cost as one of the issues that bothered his participants. Alteration in body image seem to have minimal effect on participants as compared to other challenges, however they have shared the physical

changes their body go through due to the disease or the treatment. In existentialism, existential anxiety is seen when we realize the need to struggle for survival and one's basic weaknesses. The participants in this study went through existential anxiety when they started to encounter these challenges. It is normal to have this anxiety when faced with a situation and can be used as motivation to change.

Existential anxiety has seemed to have brought about changes in the participants. They become aware of themselves and what they are capable of doing to face the challenges. Capacity of self-awareness as one of the basic dimensions of human condition according to existentialism. In expanding self-awareness, one increases the capacity to live fully. The participants have the choice to act. Hence each individual creates their own strategy to cope with the challenges. Some of the coping mechanisms they developed are through family support, spirituality, affirming actions and treatment. Family support was the most effective and best strategy that helped them through their ordeal. Social support is highly likely to impact the quality and meaningfulness of one's life by helping them to cope better with their sufferings and making them feel appreciated, respected, loved and cared for. Patients and families who have come to terms to the terminal situation seem to be able to accept the reality better. Family members are the ones who provide the most support. In another study, it was found that spending time with family increases one's quality of life. This is consistent with the finding in this study about how important family members are to them [21].

Spirituality was a common coping mechanism for all participants except for one who believes that supplements have kept her going all the while. Most believed that there was a purpose in their suffering and some even felt it was a blessing. One of them attributed his 'living' to God after his mother. They view life positively which enable them to live through the ordeal. Participants also believe it was God's plan for them to go through the illness, how the religious community is important to them and some felt that God is watching over them. Spiritual and religious support is about "relief of emotional anguish" and this is how some of the patients her participants counseled felt. In another study conducted locally, the participants also seem to repeatedly referring to God or God's will about their diagnosis or about being cured. A study conducted in Nigeria, indicated that they became stalwart in their faith and believed that strengthening their faith further can bring about miracles.

Positivity was a coping strategy that has taken all the participants on their survival journey. All of them thought positively or acted positively as they felt that it was beneficial in keeping them going. The participants preferred to speak to people who are positive, one participant finds joy in helping others who are in the same boat as her, through social media and another person feels he should advocate for treatment for those who going through the same disease. Finding positivity in negativity takes effort. While talking about the negative aspects of their illness, the participants in his study try to find reasons for gratitude and finding positivity amidst of uncertainty on how the illness will progress was their way to cope. This was also the same coping strategy the participants felt in this study. In another comparison study, it was found that people with imminent death were more positive than people who were asked to imagine to be dying.

In existentialism, death is not viewed as negative but having the awareness of death as a basic human situation that gives meaning to living. Death gives motivation to appreciate the present moment and encourages one to view it as positive energy that encourages living life fully with meaning.

Treatment and the positive response to treatment is motivating factor for some of the participants. They see hope and believe that they can get better after taking chemotherapy or supplements. They are relieved from their suffering and are happy to move on in life. The participants in his study do not believe in being dependent of medication or any kind of treatment and have their own mind set of what they want.

Ultimately finding purpose and reason to continue living is the most important aspect in accepting their situation. Their desire to live, finding fulfillment in life and familial obligations are the motivations they have found to continue living.

Their desire to live is probably the factor that makes them fight against their illnesses. Some see hope, some believe in themselves and in not giving up.

Creating meaningful experiences for the terminally ill individuals can help them to identify meaning in life, increase emotional comfort and control over how her/his illness is perceived. An individual with a terminal illness can go into existential vacuum (meaningless in life) when they do not have anything to do as they feel it is pointless. Life seems meaningless. However, a person can create meaning through engagement with what is valued and this commitment gives purpose that makes life worth living. The participant found engaging in something would fulfill their void and gives them a drive to move on in life. Finding fulfillment in things that they want to do and need to do help them to find the purpose in life. One of the studies found that the participants felt that they still have responsibility to carry out before anything happens to them. This finding is consistent with the finding with current study where fulfilling responsibility has become a priority for survival for some. Others were contented and want to live this life to the fullest. Some find such joy in helping others. Seeking fulfillment and meaning in life is achieved through engagement which is a commitment to creating, loving, working and building.

Family obligation is one of the important driving factors for most of the participants. However, two of the participants did not have the family support and felt they were alone. Nonetheless they felt that they have obligations to fulfill as a parent. This seems to be their purpose in life. Others had their full family support and felt that they should do something for them. Family involvement is widely discussed in many other studies and the importance of their presence. One study also mentions about the participants who want to ensure that everything is taken care of in the family before their passing on. A study done on the effects of social support on the terminally ill showed that the more satisfied they were with family support, the higher was the degree of meaningfulness of their life. When family shows that they have accepted the condition of their loved ones and are ready to let go, the individuals are able to let go easily.

Existentialism explains that as relational being, we yearn to be connected with others. When a person is able to stand on his/her own and tap on his/her strength, he/she will experience relationship based on fulfillment and not deprivation. Some of the participants in this study are likely to have tapped on their strength to be helpful to their family rather than depending on them.

The participants in the study did not speak much about death or dying unlike other literatures where the participants speak openly about their impending death. The participants shared about how they are going to live and carry out their plans that they have. The question that came up is have they accepted their impending death? They all had a positive mindset about life and how they were going to live it.

LIMITATIONS AND RECOMMENDATION

There was some limitation to this study. The small sample size in this study does not provide a generalized description about the experiences of terminally ill individuals. A bigger sample may be able to give more descriptive experiences and in-depth understanding of their lived experience. The age ranges of these individuals are wide apart which also may have affected the finding as they are all in different life stage where their needs and wants are different. One of the participants who were 60 years old said that her need and desires are so different from a younger person and she has nothing to worry about. The participants who were younger were more concerned about career and taking care of family while the middle aged is worried about their family. A fair distribution of age range would have yielded more meaningful findings. A fair selection of the three ethnic groups could have provided a variety of description of different religions and beliefs.

Death and dying process in cultural aspect was not shared. The participants spoke very little about death or dying which raised a concern if they were provoked to speak about death, they might have shared their thoughts about it. They may have shared their perception about death if they were asked more questions about it.

CONCLUSION

The study was done to explore the lived experience of the terminally ill individuals. It was meant to look at their lived experience in physical, psychological, social and spiritual aspect. The themes that emerged were consistent among the participants and somehow fell under one of the four aspects. Almost all participants seem to have the almost similar thoughts and emotions where the initial negative feelings have caused frustration, disappointment and some even depression. But they all managed to fight the negativity by finding their own coping strategy and purpose in life to move on with a positive mindset. This brings to mind Kubler Ross theory of grief. The participants in this study seem to have somehow have experienced the stages. Some were in denial such as one participant who refused to see the doctor. Denial was explained as a temporary defense mechanism that helps one to survive through the ordeal. Being angry with God at the initial phase was also one of the emotions a few of them experienced and subsequent bargaining, where one of them bargained for the absence of nausea and vomiting during chemotherapy. Anger as part of healing process and bargaining is creating options to delay the consequences. Some of the participants went into depression and finally all of them seem to have accepted the reality that they have a terminal illness. At this stage, one can go into an extreme emotional turmoil where he/she able to understand that what happened to them is not changing and lastly acceptance where they realize that it is reality and accept it. However, the stages came in different sequence for each individual and all of them did not experience all the stages.

Family played an important role as their support and involvement were crucial in finding meaning in life. Counselors can play their role in assisting to improve their quality of life by helping them to find purpose and meaning in their life. This study can be helpful in giving an insight to counselors on what the terminally ill individuals are experiencing and what is important to them, what can cause them distress and what gives them hope. Finding meaning or purpose in life has become the beacon for their survival journey and eventually to a probable peaceful death.

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