

How Does It Feel to Be in Isolation Room? A Narrative Inquiry of Neutropenic Patients

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Abstract: Leukemia is a malignancy disease that requires aggressive medical management i.e. chemotherapy. One of the side effects of chemotherapy on patients with leukemia is neutropenia. Neutropenia requires special handling including treatment in isolation rooms. This study is an observational study that aims to explore the experiences of leukemia patients who experiencing neutropenia during treatment in isolation rooms. The transcribed interviews were analyzed by methods of qualitative research. Participants in this research are patients currently under treatment in an isolation room or previously ever treated in the isolation room before. The number of participants in this study amounted to four participants. Research methods in this study was a narrative inquiry with data retrieval through in-depth interviews using a recorder and field notes. The results found that almost all patients feeling lonely, all patients have a misunderstanding about neutropenia and febrile neutropenia, patients have told their hopes as well as coping mechanisms during the treatment. Suggestions addressed to the healthcare worker to more often to communicate with patients as long as they are in isolation rooms, providing the patient with counseling and education about neutropenia and febrile neutropenia before, during and after treatment.

1 INTRODUCTION

Cancer is the leading cause of death in Indonesia caused by noncommunicable disease after heart disease (*Indonesia health profile: Proportional NCD 2010, 2018*). Cancer is not only solid tumors but also hematologic malignancies. Leukemia is one of hematology malignancy. Leukemia ranks the top 10th cancers that occur in men in Indonesia (Bray *et al.*, 2018). Along with the increasing incidence of cancer cases particularly leukemia, aggressive medical management needs to be held.

Chemotherapy is one of the main treatment and medical management for patients with Hematologic Malignancies that aims to fight various forms of leukemia and to prevent recurrent disease, where the drugs were given together in a set regimen (*Chemotherapy for leukemia, 2018*). Since each drug destroys tumor cells in different ways, the combination of drugs can make the cells susceptible to treatment. myelosuppression is one side effects caused by chemotherapy in leukemic patients (Rieger, 2006). Tervit & Philips (2006 in Coughlan & Healy 2008) adds that the incident myelosuppression especially neutropenia is a

cytotoxic side effect of chemotherapy in cancer patients. Other research by Crawford *et al.* (2004) mentions that patients with neutropenia have a high risk of infection.

Friese (2006) notes that 40% of chemotherapy toxicity was neutropenia and can develop into neutropenic fever/febrile neutropenia. Friese (2006) also explains that febrile neutropenia is the incidence of neutropenia with fever more than 38.8 C and lasts 7-10 days. While Seth & Bhat (2011) stated that febrile neutropenia is one of the serious problems of oncology emergencies. Medical treatment in Indonesia especially Dharmais Cancer Hospital for patients who experience neutropenia or febrile neutropenia is by placing them in a special isolation room. The impact of patient care in a special isolation room was feeling of being isolated, depressed, the patient has a stigma, requires further information, the lack of social contact, lack of contact with health care workers having a perception that physical activity was limited (Campbell, 1999).

Research related to the incidence of neutropenia in patients has been conducted. Donohue (2006) conducted a study to evaluate the risk assessment tool of neutropenia, and recommend the use of the

assessment tool in determining the risk of neutropenia in patients. Other studies conducted by Ropka & Padilla, (2007) about the quality of life of patients with neutropenia, that there were significant results in a declining quality of life of patients who experience neutropenia.

A preliminary study describing the experiences of patients who experience neutropenia has been done by Fauji et al. (2012) gained five themes, namely long treatment and care, the perception of neutropenic patients, the difficulty of self-care, the support of family and friends as well as the expectations of the patient while neutropenia occurs. Another study of adult patients who were in isolation room has been done as well as being an evidence-based practice (Rees, Davies, Birchall, & Price, 2000)

When doing nursing practices in the isolation room, the researcher observes and noted stories from patients when they experience a neutropenic fever. Based on observations, then literature searching related to the response of the patients treated in the isolation room was conducted. It resulted in a limited study that reveal the overall patient experience when experiencing neutropenia or neutropenic fever/febrile neutropenia during treatment in isolation room especially immunocompromised isolation room. The research question of this study was how does it feel being in isolation room while experiencing neutropenia or neutropenic fever?

2 METHODS

The approach has been used in this study was a narrative inquiry. Narrative inquiry was chosen because it was able to capture the personal experience that was hard to described into facts and opinion (Gail, 2006; Warne & Mcandrew, 2010). Van Der Riet, Dedkhard, & Srithong, (2012) explains the advantages of narrative inquiry as it reveals the order of the information in the description, the complex linkages with stories of past, present, and future with culture and social environment. Through narrative inquiry participants consciously tell their views in accordance with reality and include events that cannot be compared with their present interpretation (Sinclair Bell, 2002); (Warne and Mcandrew, 2010)

Gail, (2006) mentioned that story that was told was affected by past experiences, social backgrounds, and situations faced at the moment including social networking, occupation, and

personal life. Narrative inquiry requires researchers involved in research as active participants in order to listen stories being told also directly involved in analyzing of the stories (Gail, 2006; Sinclair Bell, 2002; Warne & Mcandrew, 2010). Through the narrative inquiry participants expected can express their life experiences through a story including the social environment where the events took place. The stories revealed by participants is formed due to the interaction between the researcher and participants.

The framework that is used to perform exploration research findings using Clandinin & Connelly (2000). This framework mention three aspects including temporality, community life, and spatiality. The third domain of the frameworks was expected to provide structures in conducting the analysis of narrative inquiry. The use of the framework can also provide guidance and direction in performing data analysis, namely: inwards, outwards, backward and forwards (Clandinin and Connelly, 2000). Added by Clandinin & Connelly (2000) inwards mean to find the emotions and feelings, while the outwards means to check the social condition of the surrounding which can affect the whole story. Changes in the transition to the back and forward are intended to examine the changes of emotion which take place in the story.

This research aims at exploring a patient's experiences who experience neutropenia/febrile neutropenia in the isolation room. Participants in this study voluntarily involved without having to tell their story while experiencing post-chemotherapy neutropenia or neutropenic fever in the isolation room. Patient confidentiality is maintained by the use of pseudonyms in the verbatim transcript, pseudonyms intended to provide a pseudonym or alias for each participant. Participants in this research are patients currently under treatment in an isolation room or previously ever treated in the isolation room. A number of participants in this study amounted to four participants. Data were collected from August – September 2018. Instrument that were used were field notes, digital tape recorder and a list of question for in-depth interview by the researcher.

Ethical considerations of this research was conducted through evaluation by the research ethics committee of Dharmais hospital. All participants get receive a gift from the researchers because the participants have to take their time to be interviewed. All data that were used in this research were treated as appropriate as possible to ensured confidentiality from all participants.

3 RESULTS

The results of the interview subsequently transfer into the verbatim transcript by one researchers and reviewed by another researchers. Inductive process become important in order to bring the whole integrity of the story from all participants.

The first participants

The first story told by Abang (17-year-old) students, with a medical diagnosis of Acute Myeloblastic Leukemia (AML), He has been treated in isolation rooms with chemotherapy of regimen LAM VIII. He currently under hospitalized in a ward waiting to be treated back into an isolation room.

Abang's story

Neutropenia? I didn't know[that].

I can say [that] the leukocytes will drop drastically so [that] the impact will lead to infection from outside so ... so ... necessary sterile room at RIIM [it ideally].

Now I've got a fever, the nurse told me because of my low leukocytes.

This time I was having fevers and chills, so Abang wearing blankets and gloves.

Blankets and gloves from home [which] were brought by my mom's.

If Abang had a fever like this, Abang wishes there's a family here.

There's a family but they were outside, it's there [while pointing out the window, ~~where~~ his mother sit beside the windows]

Abang wants someone to hug, and someone caress me. It seems convenient if there are families especially moms here.

Usually, if Abang has a fever, mostly Abang just use a blanket to cover my body.

The nurse will come to see and measure my body temperature and they also give me medication and sometimes nurses come to have a chat.

Communication with families rather difficult, Abang often use mobile phones to talk with them.

There is an intercom in this room [pointed an intercom that hangs on the window].

Abang rarely uses the intercom because Abang has to get down from the bed, the problem is my body is too powerless [to] getup, as well as chills and lethargy.

Lethargy may be due to anemia so Abang also receive transfusions.

If fever occurs Abang have a feeling of fear of death, of course.

I'll make it easy, the doctors also say so.

Although sometimes Abang wants a hug and caress from moms.

I like to think of things that made me happy like I have no fever, back home, and gathered with family.

Sometimes I invite a nurse to have a chat, but not too often, because I know the nurses obviously being busy, and certainly there are other patients who need her the most so rarely I have a chat with a nurse.

I like to read novels sometimes the nurses borrow mine and vice versa.

A novel, blankets, gloves, laptop or all the stuff I brought here are allowed but should have been sterilized.

I've been eight times being hospitalized in RIIM, often experience a high fever especially after chemo.

Have a feeling lonely and alone is always there but there are also feeling like to accompanied by family, being hug or caress. Eventually, as long as I been hospitalized my family had never entered the room to accompany me.

I hope that the family can get into the room, at least while the fever.

I know families were concerned. I often saw my mother pray or if I'm like this, my mother's prayer is also getting longer.

Yes, of course, I also pray, I pray for the fever went down quickly, so my family especially my mother not worried.

Well, that's it for today, I feel tired and seemed to want to go to bed.

Thank you for listening to my stories.

Analysis and reflection

Abang has the wrong concept about neutropenia and febrile neutropenia. Abang felt that as long as in isolation room he felt lonely and alone. When febrile neutropenia occurred, Abang wanted that any family could accompany him, particularly his mother. Abang wanted to be embraced by her mother. Abang stated his hope and cope while experiencing febrile neutropenia and hospitalized in an isolation room.

The second participants

The second story told by Opung (48 years old), male, civil servants, his medical diagnosis was Acute Lymphocytic Leukemia (ALL). Opung was patient who were treated in the isolation room, currently undergoing chemotherapy consolidation phase ARA-C and Daunocyn.

Opung's story

Neutropenia is blood cancer, that is that I know. It's been almost two and a half months I was here, the chemotherapy already been 21 times. The impact of the disease, not just the sick person, the dying person if God wished, they can be alive again.

My current conditions, Hmhmhm... let me see, anyway it's difficult. Now I've got a fever so... I used two layers blanket.

This room is ... (chills) very cold, cold room plus fever made me chills.

Would like to have ompung boru here to accompany me. Yes, just accompany here on the side.

Ompung boru sometimes comes because we still have young children at home. My kids often visit me here, but they also have to work, they took turns keeping at night. Ompung boru took a turn on Saturday or Sunday.

I Want ompung boru to accompany just to chat only ... yes, the point is accompanied.

I Want to be served, rubbed by her.

Family cannot enter here, mostly looked through a window, if you want to chat through the intercom, but in this condition it is impossible? to get down from a bed, to sit down already shivering.

In the isolation room, the condition is like this, alone here and no friend. It's not good. Most of the time I watched television or if there is a family to come we pray together.

The Bible there, I bring it, I read well sometimes.

I want my family could be permitted to enter the room, especially if I was in fever.

There are nurses who come, giving medicine, assess, just help me, that's it.

Analysis and reflection

Opung also has the wrong concept of neutropenia and neutropenic fever. When experiencing a neutropenic fever Opung wanted his family to accompany him particularly *ompung boru* his wife to accompany and serve him or at least rubbed him. Opung felt alone in the isolation room. Opung stated his hope and cope while experiencing neutropenia or neutropenic fever when treated in the isolation room. Opung speech sometimes could not be heard and not clear. During the interview, it could be observed that he often covered his mouth by blankets. He looked shivering.

The third participants

The third story was told by Bunda (36 years), female, private employees. Her medical diagnosis

was Acute Lymphocytic Leukemia. Bunda was a patient treated in the isolation room with chemotherapy regimen Vincristine and Daunocycin phases of ALL 80.

Bunda's Story

Neutropenic and leukemia may be the same.

Neutropenia that leukocytes will drop drastically.

Its effects on the kidney and liver because my stomach enlarges and so bloated somehow.

The nurses said it was like that, and my body temperature was high, but I did not feel a fever or chills.

Fever after chemotherapy... One time, [I] also treated in the same room.

I felt sad at this time, separated from my son if it was like this.

I want to be able to hug my son again, singing Nina bobo before bed, I want my son here I mean here with me but it is not possible, here's a sterile room, where small children are not allowed to enter.

My son always stays here with my husband at night.

In a ward there is my husband. He usually accompany me, feeding, bathing, too. Sometimes my son also came. When he comes my son does not want to go home, want to hug mom he said, he also misses me.

In this room, not only a small child, but my husband also cannot enter.

I am confident and optimistic definitely will be cured, because God does not try His people, this is just guidance from God.

In this isolation room, the most are quiet and alone.

Watching television, if there's my husband or my son comes we chat through an intercom. My son told me all kinds and everything. It is sad if my son says "mom I want a hug", So I have to get off the bed if it's permitted by nurses, and if my platelets count is not low.

I'll sit close to the windows so I can see him up close. I want to cuddle and hug my child again. that's why I'm always optimistic definitely cured.

Analysis and reflection

Bunda, as well as other participants, have wrong concepts and understandings about neutropenia and febrile neutropenia. Bunda also said that as long as she been treated in the isolation room she felt alone. Some of her daily activities were performed during treatment. Bunda hopes to embrace and sing a

lullaby to her son during bedtime. Bunda stated his hope and cope while in the isolation room.

The fourth participants

The fourth story is recounted by Mas An (34 years old), male, worker, his medical diagnosis was AML. Mas AN was a patient in the isolation room with chemotherapy regimen Cytarabine 2550 Mg day 23rd, experiencing neutropenia at day 10th to 20th during treatments in isolation room.

Mas An's Story

*I've been here is five times with the doctor S.
The term neutropenia I don't know. It is my first time to hear the term.
I think I've never been explained by the nurse or doctor.
Perhaps it's already explained, but I forgot it somehow.
Please understand, because I'm sick Mas... hehehehe (laugh)
Anyway Mas, in the beginning, it felt hurt in my back if like this (showing the position semi fowler), next to my body began to feel unwell, tired, and chills when going to the bathroom.
When it's happening at most I'm kerungkup'an (wrapping body with the blanket from the feet to the head) later fell asleep.
One time the nurse L came, he saw me kerungkup'an at night. He just asked what was going on, then my temperature being measured, then she says tomorrow will be checked again because I fell asleep.
It is better to sleep than waking up, Mas.
I know this room, I would take a rest.
In the regular care room [ward], I do not like the bathroom, there were seven Patients including who wait for them so how many, I can't deal with it, it feels like using public bathrooms. Although there are more crowded than here.
My feeling is so-so in isolation room, though quieter here but I could take a rest.
I'm used to the standalone Mas, since young, before marriage.
I am in Balikpapan work since 2002, wandering around and lives alone.
So I don't feel anything in the isolation room
The important thing is I can rest, Mas.
My wife and family do not have a problem, there isn't feels heavy.
At most, before I enter this room, at night, I eat what I really want, just like that, Mas.
I have no drawback in the isolation room, perhaps because it was normal for me to live*

independently since 2002, all alone to work in other villages just like that.

My concern in this room is very cold, and I can't be free. That's it.

I hope that my chemo will be ended very shortly, there's no complication at all.

Analysis and reflection

Mas An, as well as other participants, have wrong concept and understanding about neutropenia and febrile neutropenia. Mas An has no problem being in isolation room because he was used to be alone by his job since 2002 at abroad, but he had expressed quiet and alone. While telling a story Mas An was more excited to tell about another ward rather than in isolation room. Mas An's hope and cope while in isolation room and when experiencing neutropenia has been delivered.

4 DISCUSSION

The results of this study show that the majority of the participants felt lonely because of being in isolation rooms. These results are consistent with the research that has been conducted by Gaskil et al. (1997) that patients in isolation room will attempt to gain control over himself due the lack of control while being in isolation room, as well as losing contact with both families and health care workers or in the other word that they felt lonely. Austin et al. (2013) stated that the patient feels lonely, sad, worried, bored and need information if they needed to be hospitalized in single room isolation.

Meanwhile, other research conducted by Forsner et al. (2009) in children who experience isolation found a lack of children's interactions with friends while in the isolation room. This is in line with the research that has been conducted by Gaskil et al. (1997), Kennedy & Hamilton (1997), as well as Campbell (1999), States that loneliness, depression, the rise of the stigma, the need for adequate information, the lack of social contact, lack of contact with health care workers, as well as a statement that isolation room can cause physical barriers.

Being hospitalized in isolation room provide physical or psychological impact, especially on patients who experience neutropenia and being treated in the isolation room. The results showed that patients will experience loneliness during treatment because of being lonely in a sterile isolation room. Some patients have been using adaptive coping mechanisms during undergoing treatment in the

isolation room. Biagioli et al. (2016) stated that in general patient in isolation room felt isolated. Gammon (1999) suggested that very serious effects are noted on the psychological well-being of individuals.

The coping mechanism used by participants during treatment in the isolation room based on research such as reading, watching television, or communicate with families via mobile or intercom located in the nursing room. These results were inconsistent with the results conducted by the (Chircop and Scerri, 2018) in Non-Hodgkin's patient showed that they living emotional roller-coaster, becoming dependent on others and facing an uncertain future while their undergoing chemotherapy. Goldsack et al. (2014) reported affected hospital stay, and 28% (9/32) of patients reported emotional distress resulting from isolation. Meanwhile, on lung cancer, patient coping strategies were concealing the fact of sickness, reducing social activities, seeking medical assistance, adhering to treatment, and disclosing dissatisfaction (Liu *et al.*, 2016). Ghodratty-Jabloo et al. (2016) concluded that an integral role of the coping mechanism was needed for effective and ongoing psychological intervention

Patient understanding about neutropenia especially febrile neutropenia is still misunderstood. All four participants said incorrectly about neutropenia and febrile neutropenia. Wengström et al. (2007) suggested that greater effort was required to ensured patients understand.

Other findings show that almost all the time all participant being alone. Nursing staff or physician some time entering the room to check their conditions. But most of the time they were left alone. Mulatsih, Dwiprahasto. and Sutaryo, (2018) suggested that specific training was required for the staff nurses to improved their knowledge and skill in caring for patients.

5 CONCLUSIONS

The results found that almost all patients feeling lonely, all patients have a misunderstanding about neutropenia and febrile neutropenia, patients have told their hopes as well as coping mechanisms during the treatment. Suggestions addressed to the healthcare worker to more often to communicate with patients as long as they are in isolation rooms, providing the patient with counseling and education about neutropenia and febrile neutropenia before, during and after treatment.

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