

Life Experience of Adolescent with Leukemia, North Eastern Part of Thailand

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Abstract— *The current study aims to explore life experiences of adolescent with leukemia. This qualitative research employs the Interpretative Phenomenology, or Hermeneutic Phenomenology, along with an in-depth interview with the 15 adolescents, who received a treatment or a follow-up care at a cancer ward and a children's outpatient department of a tertiary care in the northeast part of Thailand. Data analysis is conducted with Dikelman and Allen's approach. The finding reveals 4 themes of the experiences caused by leukemia: 1) the meaning of adolescents with leukemia: life-changing, 2) life experiences of adolescents with leukemia including 5 sub themes issues, including to; overwhelm with fear, more than pain, chemotherapy and effects, living with new body image, and living with hope, 3) needs of adolescents with leukemia, and 4) Illness condition relevant to adolescent with leukemia. The research result leads to a better understanding about experiences of leukemia in adolescents. Also, the data can be used to support the practice and administration for nursing school and research in the future.*

Keywords— *Leukemia: Adolescents: Life experience: Phenomenology.*

I. INTRODUCTION

Leukemia in adolescent is regarded as a major problem of health system. In 2011, there was 32 percent of a newly diagnosed patients with cancer in the group aged 11-19 years (National Cancer Institute, 2011). The major treatment for leukemia is chemotherapy. Currently, the Thai Society of Hematology improves the chemotherapy for children to be more effective and to reduce complications (The Thai Society of Hematology, 2016). After diagnosis with leukemia, a patient will be investigating with painful medical procedures, such as bone marrow aspiration, lumbar puncture, and blood draw (Pumsrisawas, 2003). The leukemia patient is subsequently taken for chemotherapy. Despite a better response to illness, chemotherapy causes complications giving frustration to adolescents.

Nowadays, some studies focus to relieve suffering from a treatment in childhood cancer patients, like preparation program before treatment. However, these studies focus on the school-aged participants and are quantitative research. The researchers yet conduct studies as an etic view, which may not appropriate respond to the adolescent's needs. To gain profound and deep more understand about life experiences of adolescent, a study must be conducted with leukemia patients

in adolescent, who personally undergo real life experiences. The study's objective is to understand the life experiences of adolescent with leukemia.

II. METHODOLOGY

Research design

This qualitative study adopts Heidegger's Interpretative Phenomenology in order to understand the experiences and meaning of adolescent with leukemia. This experience was considered subjective and complicated. An in-depth interview is employed to collect data using a semi-structured questionnaire. Each interview takes 30-45 minutes. Other people are not to be in a room so that the participants feel free to give information.

Participants

The recruitments for participants in the research consist of: 1) a leukemia patient must be 12 to 18 years old or study in grade 7 to 12. 2) a leukemia patient must get treatment and follow-up care in a tertiary hospital in the northeastern region. 3) Parents must give consent for the participation in the study. 4) A leukemia patient must have fully intellectual competence. 5) A patient must not be first diagnosed with cancer. And 6) A patient is willing to take an interview. The researcher coordinates with a gate keeper to contact young patients and confirm their willingness to participate.

Research tools

The researcher was research instrument. While the data collection tools consist of a semi-structured interview about experience of adolescents with leukemia. The question is based on literature review and reevaluated by 3 experts. Other tools are a field note for additional issues during the interview and a voice recorder.

Data Collection

After gate keeper contacted the adolescents to give information about the study and they willingness in the study, the researcher will repeat the process to explain all details of the project and seek consent.

Data Analysis

The qualitative data about life experiences of young leukemia patients was analyzed data by using Dielkelman and Allen's seven steps method (Plodpluang, 2013). 1) read the texts from tape transcription word by word for more understanding, 2) summarize the data and categorize them in a note. This process must be performed carefully in order to make good understanding before data grouping and giving a pseudonym. 3) analyze the data from the interview, then compare and contrast them for the variety of result, 4) consider a pattern and connection of data, then correct the interpretation employing the data triangulation, literature review, and peer review, 5) compare and contrast result, 6) find the relationship of each issue and draw a conclusion considering an index or category of data, and 7) write the last draft containing significant issues.

III. RESULT

Data saturation were achieved after interviewing 15 participants. The finding of the study contains personal data and qualitative data about adolescent with leukemia experiences, classified to 4 themes as 1) the meaning of adolescents with leukemia, 2) life experiences of adolescents with leukemia, consisting of 5 sub themes: living in fear, more than pain, perception and colors of chemotherapy, living with not the same body, and live in hope, 3) needs of adolescents with leukemia, and 4) Illness condition relevant to adolescent with leukemia.

Adolescent personal data

The researcher simultaneously collects and analyzes data. When the data saturated, a collection stops. The present study has 15 informants—7 males and 8 females. The minimum age is 12 years, the maximum age is 18 years, and the average age is 14.13 years. Six patients are in a treatment process, while 7 patients are in a follow-up care procedure and 2 decide to withdraw a treatment. Every informant lives in the northeastern part of Thailand. In terms of educational status, 10 patients are still studying, 2 are suspending, and 3 has already quit school due to a satisfied degree.

The meaning of adolescent with leukemia: Life has changed

Most of the informants define the meaning of leukemia based on their perception as life is changing and different. Due to illness and the symptoms of leukemia, their life changes as follow:

School task: adolescents have been able to attend school. But when the illness arises, they cannot do that anymore. A well performance becomes poor, not understand lessons like the others; for instance, "Now, I quit school. I haven't studied since grade 5. (study in school) Sometimes, I'm blank, thinking more slowly. In the past, I could go wherever I wanted, but now, mom doesn't

allow. Because I once went outside and got infected staying in hospital for a month. So, she has been concerned since then."

(A 14-year-old participant)

Freedom: Before falling ill, the adolescents can do all activities, like hanging out and eating favorite food. With leukemia, everything is confined and controlled to prevent any complications that may occur.

"The treatment of this disease requires sense. And sense requires feeling. How to do? What to eat? (Where are sense from?) Sense ruler (pointing at his mother) I can't do what I could do. Mom will tell what to do or not to do, and I barely follow such as don't eat coconut, beef, and buffalo. I do not quite obey, like eating pork and staying late."

(A 12-year-old participant)

Physical change: from the complications and treatment: As before, patients can normally move, stand, and walk, but after a treatment, complications appear. Legs are deformed leading to abnormal walk and run. The complications from the infections cause both legs to be amputated. Therefore, this informant cannot do daily activities as usual, asking help from parents.

"I could run, but with this leg condition, I barely stand. I can't stand for a long time as before. Like in a handcraft period, it needs a long standing; a teacher would ask to take a rest. Like in a PE period, I just sat and watched other friends. I once asked mom to let doctor cut them off and put on prosthesis."

(A 15-year-old participant)

"In the past, I did everything on my own. But now, I wake up, have breakfast, and go to school. Dad gives me a ride, holds me when getting on and off a car. I later move a wheelchair to a nursing room to study with a teacher there. I'm the only person studying in this room. The others study on the third floor, where I can't get. I have no best friends in this school, but I can talk to everyone. Actually, I had best friend, but she is in another province." (Previously, the informant lived in Buriram province but moved to Sakon Nakhon province for a treatment.)

(A 16-year-old participant)

The change of family: leukemia treatment takes time up to 2 to 3 years, and a long time for each. It affects a relationship among members, causing a broken family because of parents' separation.

"As I was in hospital for a long time, and during the second recurrence, my dad didn't visit me. Sometimes, he did it very fast. Until I knew he cheated on mom when she took care of me in hospital. Then, he moved to live with his new wife in X province. Home is without dad. Yes, I'm angry, sad, and cry for mom. Sometimes, I miss him too."

(An 18-year-old participant)

Life experience of adolescents with leukemia consisting of 5 sub theme as follows:

Overwhelm with fear. After knowing the diagnosis results, most adolescents are afraid, especially of the death. It is because adolescents have a concept of cancer and death in 4 aspects, i.e., 1) Two informants' fathers died of cancer. 2) Three informants' friends died of cancer. 3) Three informants almost died experiencing the effects of complications. And 4) The informants searched information on online social media about how cancer patients die, such as

"I thought I would definitely die. I cried, felt sad, and thought I would be like dad. (Dad died of liver cancer last year.) I searched on phone finding that if a treatment works, I am alive, but if not, I die."

(A 16-year-old participant)

"I thought it was hopeless. I searched on the Internet seeing many words start with cancer. I thought it's an incurable disease. At that time, I heard about my friend. Like, he didn't care himself. He didn't continue a treatment or recover. Some were dead."

(An 18-year-old participant)

"The disease is scary. I thought I wouldn't survive. I had heavy bleeding. I was shocked, my nose bled"

(A 16-year-old participant)

"This disease is fatal. At that time, there was a song named Light Incense for Mom. A mom in the music video had leukemia. She looked into a mirror seeing nosebleed. Her mouth was pale. She wore a headscarf; her hair fell even when running fingers through. Yes, she died. I imagined to videos, movies, and dramas. Whoever has cancer will die. I thought I would be like her."

(An 18-year-old participant)

More than pain: When receiving cancer treatment process, the informants will undergo painful medical procedures, chemotherapy and its complications. The result reveals that every participant must get painful medical procedures such as bone marrow aspiration, lumbar puncture, keeping vein open for intravenous drip, and blood drawing.

The most painful procedure is a bone marrow aspiration. Sedative drug are taken during this procedure; however, some patients refuse to use it due to its side effect—nausea and vomiting. To this end, the informants are scared and suffer from the pain.

The most performed medical procedures are keeping vein open for intravenous drip and blood drawing. Owing to the change in intravenous site from chemotherapy, it is hard to stick a needle in the right position exactly in only one time.

The informants identified the least number of times in insertion is 1-2, while the most is 50. This causes an accumulated and persistent pain and frustration. The ways to go through pains are to endure and act indifferently, such as

"Scared. I'm scared of a bone marrow aspiration. It's terribly hurt. Before needle insertion, a staff asked whether to take local or general anesthesia. It's hurt but I had to endure. There was no place for a needle to pierce. Each took 1-2 times to insert needle for drug infusion."

(An 18-year-old participant)

"I chose general anesthesia for a bone marrow aspiration. I wanted to sleep so that I wouldn't be hurt. But it's slightly hurt because I woke up before the process was done."

(A 15-year-old participant)

"I frequently had my blood drawn, sometimes lumbar puncture and bone marrow aspiration. Medicine injection at back is really painful, but a bone marrow aspiration is the most one I hurt when a local anesthesia was injected. When injected, it went straight my leg. (What is straight?) It was like a long pain. After that, I felt the same like other previous times. I bore it, not cried."

(An 18-year-old participant)

"At first, I used a general anesthetic drug for bone marrow aspiration, then I woke up and vomited. From the second time, I never used it. Early, it hurts but now I grin and bear it. My mom once told me that if you think it doesn't hurt, it doesn't. If you think it's not tortured, it's not. It depends on how you think. You mustn't think it's hurt or tortured, then you won't be hurt. I tried to fool myself that it's okay. Weak! I quietly blamed myself."

(An 18-year-old participant)

"The most hurtful moment was when a nurse couldn't find veins. Then, she moved a needle, which made me hurt. So was a bone marrow aspiration. It's extremely painful. My back's heavy when I was given local anesthesia and the aspiration was performed. It's heavy like there was something over it. When a nurse pulled needle back, I felt dizzy. My leg was dizzy. (Which leg?) A left one. It moved from my left leg (the injected side) through a tiptoe. It's dull. Not so long, my legs so much hurt that I couldn't play football or any sport. It was like ache. It appeared a day after the aspiration."

(A 12-year-old participant)

"50 times for needle inserted into my blood vessel, I didn't fight. There was no left area on my body to shoot. Every nurse in that shift couldn't keep my vein open. I just reached my arm out and let them pierce. A nurse became discouraged. I felt okay. Go ahead. Did what you have to. I counted from dawn to dusk. A doctor (in terms doctor mean to both nurse and doctor) went have dining and came back to do it again. The least number of times was 7-8. Every single finger, changing each to each. Wherever can be pierced is taken. It hurt at first and I cried. I was later accustomed to it. I didn't know what to do; I only know that it was a must and I can't refuse. I cried in the

early step, but when a needle was stuck, I just went with it. I had to give up to be hurt. Go ahead, wherever you want.”

(A 14-year-old participant)

Chemotherapy and side effects: Chemotherapy is the main treatment for childhood leukemia. It does not affect only cancer cells but also normal cells. The informants cannot remember the specific name of chemo drug, except its colors and side effects. The colors consist of white, red, orange, and yellow. Side effects include nausea, mouth sores, drug smell in nose, hair loss, fatigue, and burning veins. The ways that the participants do to relieve these symptoms are eating sour fruits and soft diets, using nasal inhaler, closing face with cloth to not see chemotherapy, sleeping enough, and telling mother when feeling abnormal. For instance;

“I can’t remember its names but colors: yellow, white, red. The red one is so tiring. When a drug was injected, its smell went to my nose. I had to buy something sour to eat. I must have them during the infusion.”

(A 16-year-old participant)

“I didn’t know its name. I got a yellow drug for 3 times, one bottle each time. I took one bottle a night. When drug was given, I vomited and had fever. Drug smell went throughout my nose, then I got better. I felt really nausea until I vomited.”

(A 13-year-old participant)

“My early chemo drug was red, and Doxorubicin, and that’s it. Another one was red-orange. I get goose bumps talking about chemo drug. It’s scary. A white one was so stink that I vomited. Its smell went around my nose. So did a yellow drug. I didn’t like it. It took so long having needle stuck inside for 10 minutes. I had a diarrhea later. An orange one burnt my arm. Another one had a big needle. It hurt my bottom.”

(A 16-year-old participant)

Living with new body image: Some participants are affected by leukemia complications, both from a disease itself and a treatment. These adverse permanently change patient bodies and impact ways of living. The complications include 1) deformed ankles leading to hard walking, running, and standing, 2) vision loss due to virus infection, 3) leg amputation due to spreading septicemia causing abnormal activities, and 4) a dependent person, informant believe the treatment leading to be diabetes that need to take insulin every day. For instance;

“I was in a severe sepsis. My leg got hurt and swollen. A doctor came to check and said to cut my legs off. It’s serious. An infection spread upwards. It could travel to lungs if my legs weren’t cut. I had both legs amputated in one time. I don’t like when other people look at. I’m sad having no legs.”

(A 15-year-old participant)

“In early, I’d got red eye, tearing, and pain. When I was studying at school, the sun was shining in my eyes; it

happened then having irritate into my eyes. Then, I came to check along with blood test. A doctor reported I had CMV virus. It happened with a right eye at first. After antiviral drug injection in the second month, I still saw. My vision began losing in grade 8 and 9. But last semester, I saw no letters. It got blur. At that time, a drug was injected at my sclera. I couldn’t have chemo drug infused due to a low white blood cell count. So, they injected at an eye since there was no effects on white blood cells. After the third time, a cataract has grown in my right eye, and thereafter a left one. Although patches simultaneously grew, the right eye was more damaged.”

(A 15-year-old participant)

Living with hope: It takes a long time for leukemia treatment and needs to continuously follow the procedures. This may impact study task, which is regarded as a main duty of adolescents. The study finds out that although some periods of time of the informants are affected with the illness and treatment, they will continue a study when their health conditions get better. They also imagine their lives and futures. As a result, the participants are hopeful to get a cure and live their lives. The research also suggests that the early adolescents do not plan much about their future, but some in the late stage with the full course of treatment have had already drawn their lives. Such as,

“I am studying now at Huaiphung Industrial and Communication Education College, mechanical program. If my vision recovers, I want to study further in high vocational certificate. I just want to see letters. I want to continue the same program to fix car and furiously drive it.”

(A 16-year-old participant)

“I go to school every day. I’m afraid I can’t follow my friends. I suspend a study at the second semester of grade 7. I came back at grade 8. When I was at home, my brother took and sent homework for me. I think I will study grade 9 at Srisangwal school. It is the school for disabled. I dream to be a psychologist.”

(A 16-year-old participant)

The needs of adolescents with leukemia

Adolescents is a stage that abruptly changes both physically and mentally. Also, they have needs by age. These factors cause adolescents to adapt themselves to the changes. Due to leukemia, changes and adaptation in puberty become more complicated. The study indicates that the informants have paused a study owing to a long and consistent medical treat in hospital. Nevertheless, they want to be at school since they are concerned about study, want to meet friends, and do activities together. Going to school thus has a boarder meaning than itself. It means a society and a world of teenagers. Plus, the concern of going to school between patients and their

caregivers is different, as the caregivers are afraid of symptom arising and complications when being at school, as follows:

“I want to study, also feel for it. I want to be with friends. If I recover, I will continue studying. I’m studying at Nong Yai School. I’m suspending now. I’ll go back studying at grade 9 this semester.”

(A 16-year-old participant)

“A change happens to study. I can’t do it. I want to go ... (crying) Because of friends, I miss them, want to play with them. (crying) My best friend is Dao. We contact via Line and Messenger applications.”

(A 13-year-old participant)

Some informants cannot go to school as usual. But they still serve the role of student by following the assignments, taking them to do at home and let some members contact advisors to submit them. The informants can study in the higher grade.

“I hadn’t been to school for the whole year, but the school allowed me to take a test. After chemo infusion, I went back for test. A teacher also gave me homework back home.”

(A 12-year-old participant)

“I have paused studying since the second semester of grade 7. But when I come back, I can continue at grade 9. I didn’t go studying at grade 8. I asked my brother to get homework for me to do at home, then let him send it back.”

(A 16-year-old participant)

Illness condition relevant to adolescent with leukemia

Being ill with leukemia in adolescents causes a patient to get treatment in hospital frequently and in a long period of time. To have a quality life by age, a young patient is supported, encouraged, and helped when side effects impact in order to take care of one’s self from disease severity and complications, to do normal daily activities, and to fulfill and comfort. The result of the study indicates that every participant has mother as a caregiver during at home and hospital. Mother has a key importance in taking care of participant such as help coping with stress, control behaviors, decide together for treatment, prepare medicine, and even earn money for the fare to hospital, such as

“I could go wherever I wanted. But now, mom doesn’t me. As I went outside and got infected staying in hospital for a month. She’s afraid, so I must stay home.”

(A 16-year-old participant)

“The treatment of this disease requires sense. And sense requires feeling. How to do? What to eat? (where are sense from?) Sense controller (pointing at his mother) I can’t do what I could do. Mom will tell what to do or not to do, and I barely follow such as don’t eat coconut, beef, and buffalo. I do not quite obey, like eating pork and staying late.”

(A 12-year-old participant)

“I said I wanted to die. (crying) When I said, my mom cried. Mom never talked something nice to me. She tortured and blamed me, like why didn’t I die? Why did I live? What’s happened to me? Why did this happen to her? Once I said that, My mom told me that if you think it doesn’t hurt, it doesn’t. If you think it’s not tortured, it’s not. It depends on how you think. You mustn’t think it’s hurt or tortured, then you won’t be hurt. I tried to fool myself that it’s okay. Weak! I quietly blamed myself.”

(An 18-year-old participant)

“At that time, I couldn’t sit, only had to sleep. There was a wound in my bottom. A doctor let me recovery at home. I must avoid sunlight and walking. When being in the sunlight, my vision turned white. I saw everything in white. I thought I was blind. I couldn’t help myself. Mom did them all.”

(A 17-year-old participant)

“Since September 2018, I haven’t been to hospital. I had an appointment. Finally, I decided and talked to mom. Death is death. Let it be. I accept everything now. I don’t want to go back to hospital anymore. My mom saw on the Internet that a porcupine flower can cure cancer. It is a decoction. I drink it instead of water. It’s a bit bitter. But okay, it’s better than drug infusion.”

(A 17-year-old participant)

“I feel sorry for mom. We have no money. If I go to hospital, I must borrow from my aunts. Mom will later mow grass or rice to sell and return money. Aunties at 3Ng. (Nurses at 3 Ng cancer ward) will call to check whether I go to hospital. If I don’t have money, let borrow from the others and take at the 3 Ng ward. Sometimes, it’s not enough, so I couldn’t go there.”

(A 16-year-old participant)

IV. DISCUSSION

The meaning of adolescent with leukemia: Life has changed:

Most of the informants define the meaning of leukemia based on their perception as life is changing and different. It means change happens to every facet of life, such as education, ways of living, freedom and decision for life, including family status. It can be explained that, before illness, the informants live in a normal state. But when sickness arises, they have to get a treatment in hospital. Staying in hospital, the participants must learn and adapt to the rules and agreements of the ward. It is counted as a new situation, leading to normal life loss and stress (Omari & Wynaden, 2014). The main caregiver of the informant is mother, who deeply devotes to a role. This thus affects family (Supakijviwatkul, 2002; Wannapog, Sangperm, Kiatkamchorn, Areegarnlert & Intachote, 2002). Moreover, the image change from illness and treatment makes the patients frustrated.

Life experience of adolescents with leukemia:

The study result classifies life experiences of young leukemia patients into 5 main theme: over whelm with fear, more than pain, chemotherapy and its effects, living with new body image, and living with hope. The informants have a fear of death as adolescents own thinking development which links to a clear concept of death like adults (Bates & Keamey,2015). The more they know about the existence of cancer, a fatal disease, the more fear they have developed. With treatment experiences, the participants discover the instability. In a worse moment, they thought they were going to die. Despite those events, they still have a fear in mind (Treenai & Chaiyaware, 2006). A pain happening during the treatment is mostly from procedure for treatment and following up. The informants do not only feel painful but are also fear, frustrated, and hopeless to fight. These are considered the more-than-hurt experiences.

The most painful medical procedure is a bone marrow aspiration. It is the process that threatens using a hollow needle to twist into a bone cavity and take out a sample of bone marrow (Wong & Baker, 1988). In spite of a local anesthesia, it cannot reduce pain during the procedure (Kuball, Schuz, Gamm & Weber, 2004). The procedure that frequently causes pain is keeping vein open for infusion and blood drawing. This chemo drug infusion can irritate and affect veins, leading to the obstacle in performing operation and causing the informants a consistent hurt.

Chemotherapy and its side effects: The participants get side effects from chemo drug and reduce pain by themselves, such as if they have nausea and vomit, they will eat sour fruits. If their mouths are hurt, they will eat soft food to relieve pain in mouth. If drug smell goes around their noses, they use a nasal inhaler. Some suffering experiences from adverse reactions include tiredness, fatigue, fever, mouth sores leading to eating difficulty (Yeh, 2002; Mattsson, Ringner, Ljungman & Essen, 2007).

living with new body image: Changes from complications and treatment permanently damages the participants' bodies such as deformed ankles, being disabled with leg amputation, vision loss, and diabetes requiring everyday insulin injection. Puberty is the age that places much importance on images. A changing body that affects images also greatly impacts social perception of the young patients (Wallace, Harcourt, Rumsey, & Foot, 2007).

Living with hope of young leukemia patients: This study finds that the informants go back to study and plan for their future. These indicate that the patients have adapted themselves to illness, helping them continue their lives. Thinking and intelligence developments in this age are logical, producing a plan for future (O' Doughety & Brown, 1990). It encourages teens to have a clear path of life and can live in the way they want.

The needs of young leukemia patients:

The informants want to study because of a concern over education. This reflects that a school is more than a school, it is another world for them. Going to school help support the cancer informants to adapt themselves and achieve the study [16], moreover they are accepted from friends bringing out confidence in relationship

Illness condition relevant to adolescent with leukemia:

The present study suggests that mother plays a key role to care and support in physical, mental, and social health of the informants. She takes care of dairy routines, support and comfort, control behavior and actions, help make a decision for treatment, and earn money for fare. To this end, mother is the most important caregiver for the informants (Supakijviwatkul, 2002).

V. CONCLUSION

The results from this study reveal experience of adolescent with leukemia. The journey of adolescents with leukemia more complicate and effect to body, psychosocial and development. Nurses and health teams should consider the importance of information about illness and its correct treatment by creating media that contain appropriate information for teenager nature. The current study finds that the informants need to study. Therefore, there should be a course for young cancer patient and concretely develop it in hospital. In the other, provide learning module and set to online school for chronic children. Further researchers should bring the issues found in this study to be a part of patient assessment for young leukemia patients.

VI. ETHICAL CONSIDERATION

The present research is certified by the Center for Ethics in Human Research, Khon Kaen University, No. HE 621040. The researcher strictly conforms to the ethics such as respect for people, beneficence, and justice. Firstly, the researcher clarifies the study objectives and procedures to the participants. The patients can stop taking an interview and quit the study whenever they want, and it will not affect the treatment efficiency. Research data are revealed and presented on the whole, which participants cannot be personally identified afterwards. The researcher prepares for unexpected situations like sensitive, uncomfortable, and anxious feelings during an interview. For instance, if an informant cries, the researcher will immediately stop questioning and support his/her feeling. Then, if the informant gets better, the interview will start again. But if not, the researcher will pause the interview and make a new appointment when the patients are ready.

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