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## Leukemia and Its Impacts on the Quality of Life of a Child: A Case Study

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The purpose of this study was to allow a leukemia patient to describe their health related quality of life (HRQoL) in their own words, in order psychologists could understand the impact that leukemia has on children. Four semistructured interview questions guide the interviews. Each question related to a domain identified in previous researches as having an effect on HRQoL. Areas explored were (a) physical well-being and symptoms, (b) psychological well-being, (c) social well-being, and (d) functional well-being. Five themes were identified: (a) fatigue, (b) the effect on activities, (c) medication and treatment effects, (d) relationship changes, and (e) hair loss. In addition, based on content analysis, the result showed that there is an interactive effect between the diseases and the level of QoL. The results reveal that the social, physical and emotional health and well-being of children with acute lymphocytic leukemia (ALL) is significantly poorer than their community-based peers.

*Key words:* children, cancer, acute lymphocytic leukemia.

Tujuan penelitian ini adalah menuntun penyandang leukemia limfositik akut mendeskripsikan kualitas hidupnya yang terkait kesehatan dengan kata-katanya sendiri, agar para psikolog dapat memahami dampak leukemia pada anak. Wawancara dipandu empat pertanyaan interviu semiterstruktur. Tiap pertanyaan terkait ranah yang teridentifikasi penelitian terdahulu memiliki dampak pada kualitas hidup terkait kesehatan. Wilayah yang dieksplorasi adalah (a) kesejahteraan dan gejala fisik, (b) kesejahteraan psikologis, (c) kesejahteraan sosial, (d) kesejahteraan fungsional. Ditengarai lima tema: (a) kelelahan, (b) akibat pada aktivitas, (c) akibat pengobatan dan perawatan, (d) perubahan hubungan, (e) kehilangan rambut. Selain itu, berdasarkan analisis isi, hasil menunjukkan bahwa terdapat akibat interaktif antara penyakit dan tingkat kualitas hidup. Hasil menunjukkan bahwa kesehatan sosial, fisik dan emosi, serta kesejahteraan anak penyandang leukemia limfositik akut lebih rendah secara bermakna daripada teman sebayanya di masyarakat

*Kata kunci:* anak, kanker, leukemia limfositik akut.

In Indonesia there has been an epidemiological and demographic transition in the health field regarding diseases. If two decades ago the main focus of health problems is communicable diseases, currently the focus has shifted to non-communicable diseases. The change of lifestyle, environmental conditions, as well as disease patterns and interactions between these factors has led to increased incidence and prevalence of non-communicable diseases. One of the non-communicable diseases which increase in prevalence over time and lead to increased mortality in some countries in the world is cancer, including Indonesia.

Cancer is a disease caused by abnormal and uncontrollable mutation of body cells that affect bodily functions. Cancer that afflicts children is relatively rare when compared

to cancer that afflicts adults, though it is estimated that 130 children from 1 million children in the world, at 0-14 years of age, are suffering from cancer (Keene, 1999). In general there are several types of cancer that affects children, such as blood cancers (leukemia), brain cancer, eye cancer (retinoblastoma), lymph node cancer, cancer of the nervous system, muscular cancer, endocrine gland cancer, and bone cancer. Of the many types of existing cancers, leukemia is the most common cancer among children.

On the one hand, there is indeed a potential cure of cancer among children, but on the other hand, children have to face various challenges that are not easy. Children with cancer must not only face developmental tasks and growths as children who do not have cancer, but also must cope with the impacts of the cancer they have (Belson, Kingsley, & Holmes, 2007). Belson, et al. showed that a child who has been declared cancer experienced acute stress, pain, fever, headache, flu, and feeling disgusted with the healing process

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itself. Children with cancer experience pain not only profound in his/her physique, but also experience psychological problems, such as the existence of a fairly high anxiety, worries about illness, and disruption of interpersonal relationships with peers, siblings, and parents.

Through this study, researchers hope to explore and report the true state of quality of life of a child that has been suffering from cancer at an early age. The problems in a child with cancer are not only a physical problem, but also accompanied by psychological, social, and functional problems, which affect the overall quality of life. A qualitative approach method was conducted in order to present the whole-life-story of the informant. Besides of that this paper was presented to give a more humane picture of the quality of life of a child with leukemia. Narration about informant also illustrates that being a person with a terminal illness like cancer does not mean the end of everything, because he/she can still continue to be his/her true self.

## Quality of Life

According to the Post, Witte, Schrijvers (1999), there are three ways that can be used to operationalize the concept of quality of life, that is to see the quality of life as health, well-being, and as a global construct (superordinate construct). In medical research, quality of life is often considered synonymous with health. Some researchers then used a more narrow term of "health related quality of life" or "health status." "Health related quality of life" is seen as part of the overall concept of quality of life (including part of the quality of life associated with the individual's health).

## Health-Related Quality of Life (HRQoL) and Its Dimensions

Kaplan (cited in Garrat, Schmidt, Mackintosh, & Fitzpatrick, 2002) defines quality of life of patients with chronic disease as "...the impact of disease and disability upon daily functioning." Gotay (cited in Garrat, Schmidt, Mackintosh, Fitzpatrick) defines quality of life as a welfare state which consists of two components. First, daily activities which reflect physical, psychological, and social well-being. Second, one's decision on the functions of life and symptoms associated with the disease and its treatment. Other researchers mention that the quality of life is a gap between expectation and experience of one's health (Carr, Gibson, & Robinson, 2001). Given the many different definitions of health-related quality of life, it can be concluded that quality of life is a multidimensional concept including physical, psychological, social, and functional which were associated with disease and therapy.

## School Age Children

According to Erikson, in terms of psychosocial development, school age children are at the stage of industry versus inferiority (G. Feist & J. Feist, 2006). At this stage, self-esteem of children is strongly influenced by the ability of mastering certain skills that are taught by their environment, such as reading, writing, or using a computer. The child will feel accepted by the environment when able to produce something of the skills they have learned (industry), but when they fail to do so, then they will feel inferior (inferiority) (Shelly, as cited in Sidabutar, 2008).

At this age, children also begin to become aware of the feelings of others and their own. Children learn what makes them afraid, angry, or sad, and how others react to the expression of these emotions, and then the child learns how to regulate emotions in social situations. Children also can respond appropriately to others who are depressed (Saarni, Mumme, & Campos, as cited in Papalia, Olds, & Feldman, 2001). Children who are in this stage usually begins to spend more time outdoors and learn to be away from their parents than previous age stages (Hofferth, as cited in Papalia et al.).

## Impact of Cancer on Children

Children's understanding about cancer and its developmental stage greatly affect how children cope with the disease (Sourkes & Proulx, 2000). Emotional reactions in school age children newly diagnosed with cancer include fluctuations in mood, feeling different from the others, thoughts of death, and regressive behaviors. According to Sourkes & Proulx, there are several variables that influence the emergence of depression or stress in children who experience chronic diseases such as cancer, namely certain stage of development, deformity (body shape changes) or disability, treatment and all the pain it causes, and prognosis (prediction of disease's impact on patients).

## Leukemia

Leukemia is a malignant disease of blood cells derived from bone marrow, characterized by proliferation of white blood cells with the manifestation of abnormal cells in the peripheral blood. In leukemia there is disruption in the regulation of leukocyte cells. Leukocytes cells in the blood proliferate in an uncontrolled way and their function becomes abnormal (Permono & Ugrasena, 2005).



Leukemia can be divided into four types, namely acute lymphocytic leukemia (ALL), acute myelogenous leukemia (AML), chronic lymphocytic leukemia (CLL), and chronic myelogenous leukemia (CML). Of the four types of leukemia, the researchers choose a child with ALL type of leukemia, because this type represents 25 percent of all cancers suffered by children under 15 years old and assumed to have a fairly high cure rate.

## Method

This study uses a single case approach, which includes a number of measurements in order to conduct a very thorough examination of a case. An interpretive paradigm was used to analyse the social action of the individuals in a natural setting, and how they create and maintain their social world could be understood and interpreted.

### Informant Selection Technique

Informant in this study is a school-age child suffering from leukemia. The informant was chosen using purposive sampling method that is based on some specific criteria as follows:

**Inclusion criteria:** (a) Aged 8-11 years (middle and late childhood). The first selection criterium for informants is at 8-11 years of age, because at that age, children are able to understand the illness and make its own judgement which is still practical and rigid. (b) Suffering from leukemia. (c) Complete a minimum of 6 months of medical therapy.

**Exclusion criteria:** (a) Undergo the process of medication in addition to the process of medical therapy for leukemia. (b) Being on stage "to receive" based on the theory of dying proposed by Kubler-Ross (1998). (c) Have a fairly severe psychological disorder (e.g.: schizophrenia, etc.). (d) A poor perception of leukemia by parents that may affect the child's psychological state.

### Data Collection Technique

Assessments conducted in this study aims to obtain accurate data about the characteristics of the informant in this study. In addition, this assessment also aims to identify the individual factors, family, and, or the environment that could potentially form, affecting, or improving the confidence, affection, and behavior that follow. Table 1 explains the details of the data collection techniques performed in the study.

Table 1  
*Data Collection Techniques*

Instrument	Selection of Informant	Measurement of Quality of Life	Problems Identification
Observation	√	√	√
Interview	√	√	√
Oncology Module-KINDL Revised Version		√	
CDI		√	
CPM	√		
SCII			√
DAP	√		√
BAUM	√		√
HTP			√

### Profile of the Informant

This research was conducted with a single informant, namely Rasya, a ten-year-old child with acute lymphocytic leukemia. Rasya's skin tends to tan. His body is good-shaped, with height  $\pm$  145 cm and weight 47 kg. His hair looks thin, straight, and cut short. His stomach looks a bit bloated.

When viewed at a glance from the physical attributes, it is not obvious that Rasya have a chronic illness such as leukemia. His hair never fall out even he has undergone several chemotherapy sessions. There are no signs of injections or other invasive medical treatment in his body. In general, Rasya looks the same as other children at his age. Until now, Rasya still undergoes chemotherapy and takes medication. Once every few weeks he undergoes a routine examination at the hospital.

But, when observed more closely, leukemia caused negative impact on the appearance of his body. Rasya lips look dry and cracked due to side effects of drugs consumed nearly a year. His face looked pale and his stamina tends to be low. This also causes Rasya to be easily getting tired compared to other children in general.

Rasya's current physical condition is very different from that of a year ago when Rasya was first diagnosed with leukemia. The researchers know that from the pictures shown by his grandmother when he was being treated at a hospital to undergo chemotherapy. In the pictures, Rasya looks thin, with sunken cheeks and a pale face.

### Personality Scheme

Table 2 shows the data collected by the researchers in order to provide an overview of the informant of this study.

Table 2  
*Recapitulation of Data Collection Results*

Assessment Findings	Data Source
Potential Intelligence and Thinking Style	
Rasya's intelligence level was classified above the average on the category definitely above the average in intellectual capacity. This high intelligence potential makes him capable enough to make good adjustment in his life.	CPM Test
Personal Adjustment	
Rasya have a high need of recognition from others. But his fear of failure makes Rasya appears as a cautious child and makes him feels the symptoms of anxiety.	Observation, BAUM, DAP.
There is sadness and unhappiness which are stored deeply in his heart. This grief is associated with the diagnosis of his illness, causing depressive symptoms and manifested in low levels of overall quality of life.	Anamnesa, HTP, DAP, Questionnaire: Module-KINDL <sup>R</sup> Oncology Revised Version, CDI.
Social Adjustment	
Rasya's feelings of inferiority make him grow into a child who likes to criticize others. This is the way in which Rasya do to mask his feelings of inferiority. The assumption is that by doing criticism to others, it will make him feel superior. This is an indication of the compensation of tend-to-be-negative self-concept.	Observation, BAUM.
Need for affection from father figure	HTP, SCII.

## Results

### Description

The assessments reveal that Rasya has low quality of life. This was obtained from measurements using *Oncology Module-KINDL<sup>R</sup> Revised Version* and CDI with observations and interviews. Rasya has low quality of life due to the suffering from leukemia since more than a year ago. A chronic disease such as leukemia tends to limit the physical and cognitive abilities. Rasya's physical conditions that tend to differ make him feel less confident because leukemia reduces his movement. As he states:

"*Gampang capek, nggak bisa ngapa-ngapain. Nggak enak. Nggak kayak anak-anak lain. Mainnya sedikit. Belajarnya juga. Beda. Nggak kayak teman-temanku. Nggak sempurna.* (Easily tired, can not doing anything. Not comfortable. Not like other children. Bit playing. Learning as well. Different. Not like my friends. Not perfect.)"

(Sunday, January 23, 2011)

Physical problems experienced by Rasya not only arise as a result of the disease itself but also due to side effects of the treatment. In the end, it appears that Rasya who have physical symptoms above will not be able to run his social role adequately and can not have quality of life as high as other children who do not suffer from these symptoms.

The low quality of life of Rasya was not only formed from the disturbed physiological aspects but also because of the negative interpretation of his life. This is due to his limitations in displaying cognitive and physical abilities. This impairs Rasya's self-concept growth and affects the overall quality of his life. Furthermore, this creates internal conflict within Rasya because his inability hampers the fulfillment of his need for achievement as well as causing disruption on his achieving self and private self. His low self-concept is manifested in behaviors such as often criticized others. This attitude is basically a compensation of the self-concept that tends to be negative. By criticizing someone else, he feels superior to that person (see Figure 1).

### Problem Framework

Rasya experienced several problems that lead to emotional disorders and affect his quality of life. This emotional disturbance stems from several factors that influence his personal perceptions and create negative interpretations that led to the emergence of cognitive distortions. Figure 1 describes the details. Furthermore, the following sections explain several aspects of quality of life and psychological dynamics of Rasya based on figure 1.

### Physical Well-Being

There is some problems in children with chronic illness in building relationship with friends, such as: physical appearance, friends' acceptance, competition, anxiety

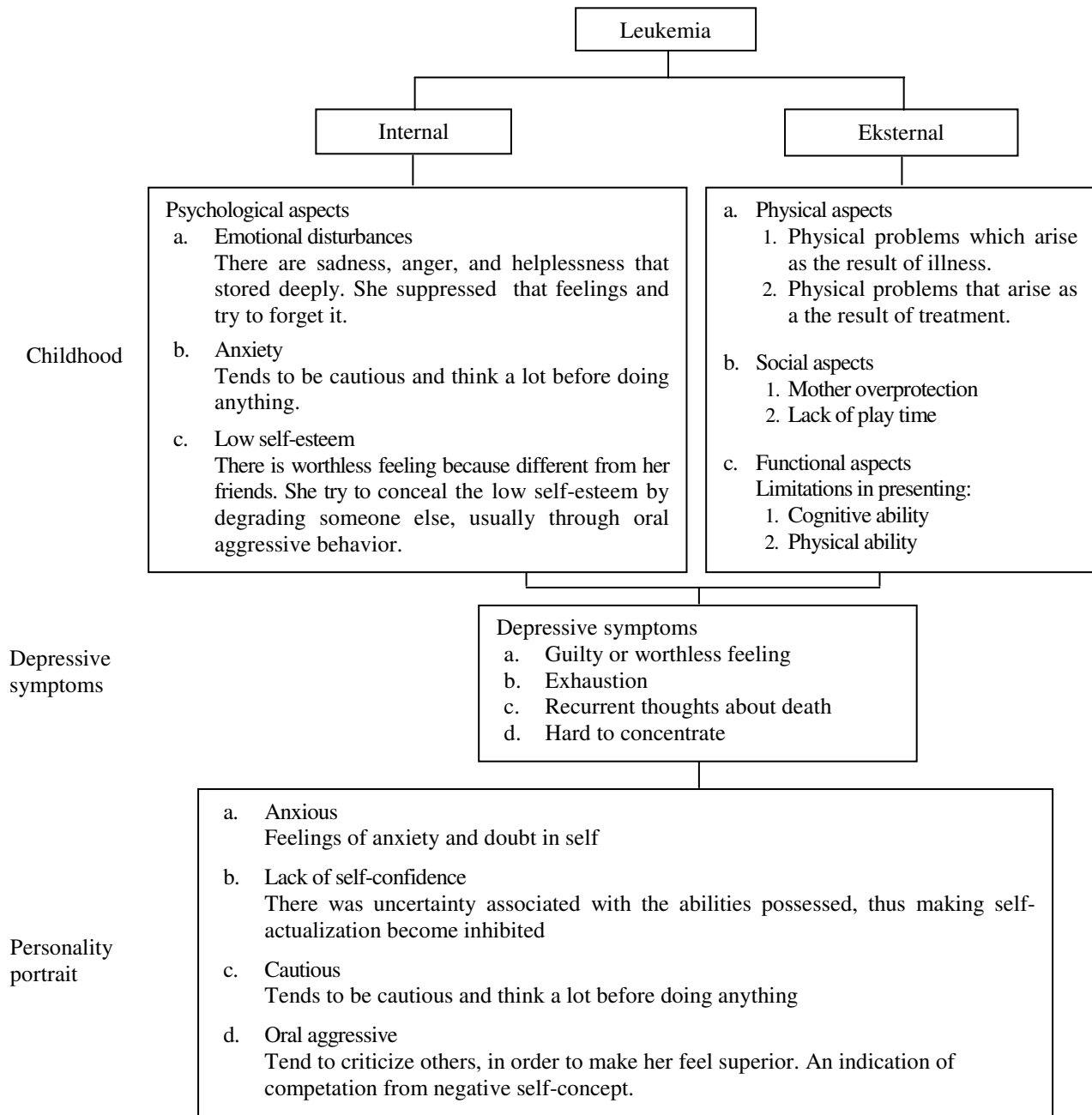


Figure 1. The dynamics of Rasya's problem

about school achievement, sports skills, and also sexual development. This is due to chronic diseases such as cancer. Cancer limits physical and cognitive abilities of children and often forcing children to be absent from school, thereby reducing the child's success in his/her study. They also lose the opportunity to develop their *self-esteem* (Weitzman, 1984). In line with the explanation by Weitzman, Rasya also experienced similar problems when faced with his daily life after coming home from hospital. There are feelings of anxiety and worry when he

first knew his cancer diagnosis; from thoughts of death, mood fluctuations, to feel different from other children.

Rasya's physical conditions that tend to differ make him feels less confident because of leukemia reduces his movement. Rasya was aware that leukemia requires him to realize his limitations in terms of physical activity, diet, and so forth. He should not be too tired because he is still susceptible to infection. Other physical activities that he should avoid are vigorous exercises like running and swimming. Both activities





*“Awal masuk pertama, memang berak terus, mencoret terus, mencoret terus gitu, mencoret. Aku mencoret terus. Nggak kayak berak-berak biasa, maksud’e kental gitu, cair airnya. nggak bisa jalan, kaku-kaku, kemeng gitu, linu-linu, mual. (When I came in I suffer from diarrhea, it’s on and on diarrhea, I continue to defecate, diarrhea continues, diarrhea continued so, diarrhea. I continued diarrhea. Not like ordinary faeces, diarrhea, I mean so viscous, liquid water, can not walk, stiff, rheumatic pains, nausea.)”*

**Emotional Response to Chronic Disease.** Diagnosis of chronic diseases was accepted as a very severe shock in Rasya's life. Within minutes, everything in his life suddenly changed. All plans, ranging from what will be done tomorrow until what would be done in the future, begin to change. So many problems fill his mind. Emotions that most often arise in these circumstances are fear and denial. Then, depression and anger become more prominent. Kubler-Ross (1998) also suggested the

same thing, but adding a fifth stage after denial, anger, supply, and depression, namely: acceptance. The five stages proposed by Ross are called the psychology of dying.

**Denial.** Denial is a defense mechanism of patients with chronic diseases such as Rasya. At this stage the patient avoid the reality of the disease and its implications. Denial is a common reaction to chronic disease, such as heart disease, stroke, and cancer (Kubler-Ross, 1998). In Rasya, denial begins at the time he felt anxious during the emergence of clinical symptoms and culminated when entered the treatment room. At that time Rasya act as if the disease was not severe and the impact of that disease was only mild. Rasya had assumed that clinical symptoms he experienced were not something serious, did not need any medical efforts to overcome them. His denial brings negative effect because it made him postpone the treatment. This sort of thing is found in many cancer sufferers (Kubler-Ross, 1998). On the other hand, this was not only experienced by Rasya but also by his mother. At that time his mother thought that the symptom was just ordinary fatigue so that she did not went to see the doctor.

In the past, denial is considered as a primitive defense mechanism and does not work, which only temporarily cover up anxiety. But recently, in addition to loss, denial is also considered beneficial to protect the individual against the crisis. For Rasya, denial serves to protect him from the problems that brought by the disease at the time he could not deal with it. Denial can also cover the terror caused by the illness, until he becomes accustomed to the diagnosis and have a better ability to realistically face the limitations caused by illness. Kubler-Ross (1998) argues that the denial encourages the patient to develop defense mechanisms to fight threats and feelings of helplessness they perceive.

**Anger.** Anger is also a common response to chronic illness, and as well as depression, the onset was usually delayed. In the early stages of the disease, the patient was too afraid to feel anger or, still having denial which inhibit the reaction of anger. But after the impact of the disease began to be felt, the patient began to wonder, "why me?" "Why should I get the disease, while there are still so many others who should be more feasible to get it?" Anger also placed at doctors and nurses. But usually, as time goes by, anger decreased.

What was described above was also experienced by Rasya. This is evident from the demands of anger, complaints, and needs to be given high attention. Even now this stage is still not fully passed. Rasya sometimes still feel anger, interchangeably with other stages.

**Bargaining.** Bargaining stage is the stage that is actually very helpful even though it happened only for a few moments. When individuals are unable to face the sad reality, he/she use a maneuver that may delay the occurrence of the unexpected. This process is done implicitly by Rasya in his prayer. The hope is to live longer, followed by expectations for not feeling physical pain. Rasya promised to better his worship and behaviors, as God give him the opportunity to live longer.

**Depression.** Depression is a common reaction and often detrimental for chronic diseases. About a third of people with chronic diseases who were treated at the hospital reported the presence of moderate depressive symptoms, while another quarter suffered from severe depression (Ross, 1994). There are experts who argue that depression is most felt immediately after diagnosis, while other experts argue that depression became more severe after patients with chronic disease are fully aware of his/her helplessness (Belson, et al., 2007). Similar like denial, depression can be useful for some purposes of treatment and inhibit others. In general it can be said that the loss caused by depression far outweigh the benefits.

Although there are enough facts that depression arise after the patient experienced denial and anxiety in the process of adjustment to the disease, but what happen to Rasya is that depression arises and sinks interchangeably with anger and bargaining during the process of adjustment to the leukemia that happened to him.

During the acute phase in hospital, Rasya did not fully understand what the impacts of the illness are. Soon after returning home Rasya face the fact that the reality was far different from what he imagined. If previously Rasya plan to do various things after returning home, then in reality Rasya realize that he can not do many things. His physical and mental strength was so limited, so Rasya became very depressed. Rasya also face the fact that it is not easy to change the habits of life as suggested to him.

Factors that act as triggers of depression in Rasya influenced by physical factors and psychological factors. Physical factors, for example, are the severity of the disease, the magnitude of the pain and the number of disability after illness; while psychological factors are other negative life events and social stress. Physical factors can better predict the depression that arises in early chronic disease, whereas more psychological factors can explain the depression arising later.

**Acceptance.** Self-acceptance according to Kubler-Ross (1998) is a condition when individuals reach a stage where he/she no longer feel depressed or angry at his/her fate. This can happen if individuals have enough time (for example, did not experience sudden death) and

being helped to get through the earlier stages. Individuals will reflect at the end with a certain expectation level.

Acceptance must be distinguished from the stage of the danger. Acceptance is more of a feeling of emptiness. It is as if the pain is gone, the struggle ended and came to rest at last before a long trip. It is also a time when families need help, understanding, and support more than the patient.

Apparently, acceptance did not occur yet in Rasya. This is because Rasya is still spinning in the four previous stages, alternating between each other.

### Patient Beliefs About Chronic Disease

To make a satisfactory adjustment to illness, Rasya must integrate leukemia into his life. This is because almost all chronic diseases demand changes in activity and life management. Rasya needs to face the disease and its resulting restrictions realistically to be able to make good adjustments. This is in line with the explanation from Keene (1999), that the behaviors associated with disease are the result of a series of decisions based on the way the individual views his/her current health and illness situation.

Results showed that patients who have a poor perception about the disease also experience a higher emotional turmoil, less quickly or even not working again, and have less involvement with the community compared to patients who have a better perception of the disease (Keene, 1999).

**Beliefs about the nature of the disease.** These beliefs include the factors of identity, cause, duration, and consequences of the disease. Identity related to the name and the symptoms of the disease. Cause means factors which cause the disease according to individual beliefs. Duration is the length of time the disease will happen as predicted by individuals. And the result is the extent to which individuals estimate the impact of disease on his/her life.

Rasya assumes that the cause of the illness are bacteria and harmful chemicals in the environment and also because it is God's will. According to Rasya, no one is needed to be blamed for his illness. But on the other hand Rasya also blamed his own behavior as the cause of the illness. There is remorse because Rasya considered himself often consume foods that are unhealthy. Rasya also worried if the disease is also experienced by his offspring later.

*"Ibu Rasya: Cuma nanya, apa dulu ada saudara yang pernah sakit seperti ini. Mungkin dia (Rasya) ngambil kesimpulan sendiri yah. Terus, dia sempat nanya, besok kalau aku menikah, kan anak saya.. gitu. Tapi kan tidak seperti itu. Mungkin Tuhan beri jalan yang lain, lebih baik dari itu. Makanya kamu harus berdoa. Supaya ada mukjizat dan itu nggak akan dikasih ke keturunan kamu."*

*Sempat nanya seperti itu. (Rasya's Mother: He just asked, is there any relatives who ever had illness like this. Maybe he (Rasya) made his conclusion himself. Moreover, he also asked, someday when he got married, whether his child would suffer from the same illness. But it's not like that. Maybe God determines another way, better than that. So you must pray. So that there is a miracle and it will not be given to your descendants. He was asking like that.)"*

(Sunday, December 12, 2010)

Leukemia indeed makes Rasya's whole life changed. Moreover, Rasya himself was unable to estimate when this disease will be cured. But the impact is really felt by Rasya, because of the limitations of activity and costs of expensive treatments.

### Conviction if the disease can be controlled or not.

In general, individuals who have a belief that their illness can be controlled generally act more adaptive when compared to individuals who do not have that belief. On one hand, Rasya assumes that this disease can not be controlled, because the pain can come any time. But on the other hand, the support from his mother who said that this illness could be cured through a strict diet and maintaining activity patterns developed Rasya's confidence that at least he can prevent the relapse, although the pain is still felt.

### Coping Response

According to the coping stress model from Cohen and Lazarus (as cited in Ogden (2004), recovery outcomes are determined by individual assessment and interpretation of stressful events (in this case it is the degree of perceived stress due to leukemia), strategies and coping response to stress, resources availability, social support, other life stressors, general style of coping with stress, and personality factors possessed by individuals. The process that occurs in this model can be seen in Figure 3.

For more details, the following is the explanation on the response to cope with stress by Rasya: Blood is a symbol of life, therefore all damages to the blood is perceived as a threat to himself and all aspects of his life. Thus, the leukemia is almost always perceived as a stressful event. Immediately after diagnosed with leukemia, Rasya started doing assessments and interpretations of his illness. Rasya's understanding of cancer and its stages of development eventually influence how he faced his illness. Primary appraisal showed that Rasya is in huge trouble. This is what makes him

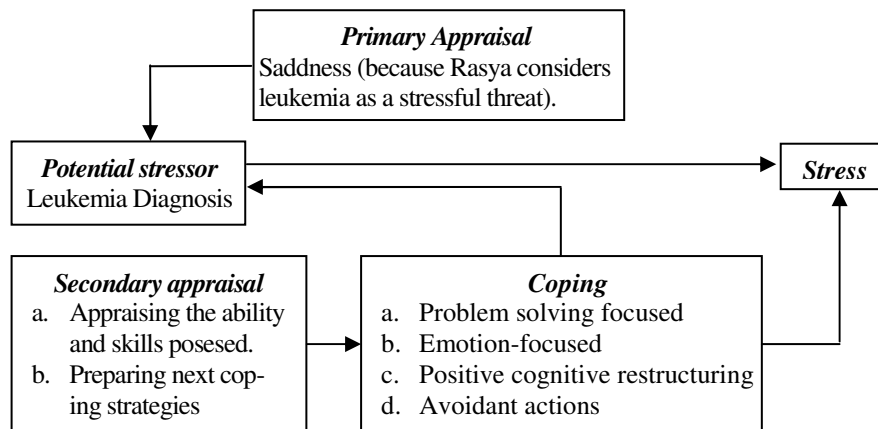


Figure 3. The role of appraisal in stress (Cohen & Lazarus, as cited in Ogden, 2004) in Rasya's case

feel the turmoil and also sadness at the same time. In the end Rasya tend to eliminate the thoughts and feelings which are not pleasant and decide not to think things that are unpleasant.

Leukemia and the possibility of relapse is always threatening Rasya's life in the future. It gives rise to psychological stress. Threat in the future which is associated with the disease and treatment are: 1) a threat to survival, 2) threats to bodily integrity and enjoyment of life (physical disability, permanent physical changes, pain, discomfort state, symptoms of disease, negative symptoms of treatment, disability); 3) threats to self-concept and future plans (uncertainty about the course of the disease, loss of autonomy and control); 4) threats to the emotional balance (dealing with feelings of anxiety, anger, and other emotions arising from stressors); 5) a threat to the fulfillment of social roles and daily activities (the loss of important social roles, dependency on others); and 6) threats associated with the adjustment to the new physical or social environment (such as adjustments to the hospital environment, problems in understanding medical terms, the pressure to make decisions in a distressed and unusual situation).

After the assessment of the primary, Rasya then made a secondary appraisal of his capabilities and skills. Rasya assesses the financial situation, help, and support from family members and other friends, as well as the difficulties he faces everyday. Style of dealing with stress that is usually used in dealing with the problems of life and personality factors also determine the strategy chosen to cope with stress.

Strategies used by Rasya to cope with stress are trying to find information related to the disease and treatment and minimize the causes of the negative impacts of the disease. For instance, by keeping all types of intake consumed by him. As told by Rasya as follows:

*"Makannya dijaga terus. Segala yang dimakan itu, yang dikonsumsi itu, segala itu harus. Nggak boleh capek. (Eating wacthfully. Everything that are eaten, or consumed, all should be watched. Must not be tired of keeping it.)"*

(Sunday, November 26, 2010)

What Rasya did is basically in accordance with the general knowledge of school-age children who begin to understand the processes of bodily functions and cause of a disease. His initial understanding of the causes of the disease is contamination, that someone is careless or external objects causing physical illness. This is why Rasya always maintain his diet and activity so he will not experience relapse. As suggested by Perrin and Gerrity (1984), that the uniqueness of the children at this age is that they hope that if they take care of him/herself and follow the doctor's advice and treatment procedures they will be cured.

### Changes in Self-Concept

The concept of self is a self-evaluation on various aspects of the lives of individuals, including "physical self, achieving self, social self, and private self." Physical self or body image is the perception and assessment of a person's physical appearance and function.

Physical aspects of self within Rasya was disrupted due to leukemia which made him experiencing physical problems, the value of the problems that arise as a result of the disease itself, such as fatigue, anemia, and various side effects from medication to physical problems that arise as a result of treatment of the disease, such as relating to restrictions on activities and changes in diet.



*"Gampang capek, nggak bisa ngapa-ngapain. Nggak enak. Nggak kayak anak-anak lain. Mainnya sedikit. Belajarnya juga. (Get easily tired, can not doing anything. Not comfortable. Not like other children. Too little playing. Learning as well.)"*

(Sunday, January 23, 2011)

The next aspect is achieving self. Achieving self is achievements in work and activities outside work, such as hobbies and leisure activities. Basically Rasya also need a means to demonstrate his competence in order to acquire some achievements and foster achieving self within him. However, since suffering from leukemia, opportunities to show his cognitive and physical abilities are very limited, thereby disrupting the growth of his self-concept and affect his overall quality of life.

*"Dulu aku kalau les bisa tiap hari, sekarang nggak bisa. Semenjak sakit jadi dibatasin. Biar nggak capek. Kemarin rabu juga nggak masuk (sekolah), soalnya diare. Apalagi waktu awal-awal. Nggak enak. (I used to have private lessons every day, now I can not. It was limited since I got sick. So I'm not too tired. Last Wednesday I also did not go to school, because of diarrhea. Even more during early-onset time. Not good.)"*

(Sunday, December 12, 2010)

Problems in achieving self is found in many cancer patients such as Rasya, with respect to living habits that need to be changed by reducing involvement in a number of specific activities.

The next is social aspect of self. Social self is a third aspect in the formation of self-concept. Rebuilding the social self is also an important aspect during adjustment after chronic illness. Fear of loss of support from family and friends are common among patients with chronic diseases (Phipps, 2007). Therefore, the family participation in the rehabilitation process is highly recommended. In this case, Rasya was lucky enough to get full support from the family members during the treatment process. This makes him quicker to make adjustments as he gets a pretty good social support.

Private self such as ambition, goals, and desires in the future also influences Rasya adjustment to his illness. It is important for Rasya to know which of the plans and dreams that can not be implemented as a result of illness or medication restrictions, and look for other alternatives as substitutes for the ambitions and future plans.

From the description above, it appears that self-concept can be affected by chronic illness. Although initially it is difficult to make a sudden change in self-concept, but in the long term adjustment can be made successfully. However, chronic diseases and their consequences often require a complex adjustment.

## Social well-being

The impact of chronicity of a disease in children on their socialization, cognitive and emotional development, depends on the age of onset of the disease and the restrictions by the disease at every stage of child development. For instance, at school-age children who had cancer, different problems will be found if the disease only began to arise during the school age than if the disease arises as adults.

In Rasya, a striking change is the feeling of low self-esteem and emotional disturbances. Rasya also become very dependent on others and use the illness as an excuse to get everything he wanted. Rasya become more aggressive and demanding more attention, especially from parents.

*"Ibu Rasya: Cepat emosi gitu. Kan emosi.. Nggak tahu juga apa penyebabnya. Kadang-kadang kalau terasa lapar, kadang-kadang pelampiasannya emosi gitu.. Yah.. Tahu seperti itu kan setelah jalan beberapa hari. Ohh.. Anak ini pas lapar juga sih. Kadang-kadang sudah kenyang, emosi. Yah.. Nggak tahu juga sih penyebabnya apa. Apakah capek.. Atau karena apa.. Gitu. Gampang sekali, gitu lho. Kalau dulu kan anaknya.. Orangnyanya juga nggak begitu, gitu lho. Ya.. Biasa. Tenang-tenang aja. Marah itu jarang. Kadang-kadang kalau hatinya anu.. yah.. bisa nerima. Tapi kadang-kadang kalau nggak anu yah.. marah. Kadang. Kadang-kadang seperti itu. Kalau nggak boleh gitu.. Ya, sudah! Gitu. Terus dilempar. (Rasya's Mother: Easily gets emotional. Dont know what causes his rage. Sometimes if he feels hungry, sometimes his emotions blow. Well ... Know it after a few days. Ohh... this boy is hungry. Sometimes when he is full, his emotion blows again. Well... Do not know what the cause. Is it tired ... Or because of what ... very easy to be emotional, you know. He wasn't like that before. His personality is also not so, so you know. Ya... Ordinary. Calm, calm. Anger is rare. Sometimes when his heart-and-so... yah... can accept. But sometimes if not-so yah... angry. Sometimes. Sometimes like that. If I say no... He threw things away.)"*

(Sunday, December 12, 2010)

Activity limitations, often absent from school, or unpleasant and expensive medication make Rasya's social wellbeing disturbed.

*"Awalnya itu memang sering masuk, ndak, masuk, ndak. Memang masih.. Ya.. Apa yah.. Baru keluar dari rumah sakit. Pas awal-awal itu malah nggak masuk sampai lama. Nggak tahu berapa bulan. Soalnya kan diopname. Nggak enak. Sendirian. Bosan. (Initially I was often present in school, then absent from school, going back to school, absent again. It is still... Yaa... What is it...? Just out of hospital. At the beginning he did not even go to school for a long time. Do not know how many months. Because he was hospitalized. Not good. Alone. Bored.)"*

(Sunday December 12, 2010)

The frequent absentee from school makes Rasya far behind his friends in certain subjects and lead to decreased performance, especially at the beginning of his illness. Rasya also can not do his daily activities such as sports or play freely and thus affects his quality of life.

### Functional well-being

One major social role in society for a child is being a student. In assessing individuals with diseases such as leukemia Rasya, the role of objective aspects of this concern are absenteeism, school full-time or part-time, relationships with friends and teachers. Satisfaction with various situations at school is also important.

School for Rasya is a place to show his abilities, accomplishments, and foster a sense of competence. At this stage, self-esteem is greatly influenced by the ability to master certain skills that are taught by their environment, such as sports, reading, writing, or using a computer. As noted by Shelly (1982) that a child will feel accepted by the surroundings when producing something from skills they have learned (industry), but when they fail to do so then they will feel inferior (inferiority).

Rasya who is in a stage of industry versus inferiority also need a means to demonstrate his competence and develop a sense of competence. But since suffering from leukemia, chances to show his cognitive and physical abilities are limited or even lost altogether. Physical conditions that tend to be easily got tired making him unable to follow some extracurricular school activities like sports and scout. Rasya was sometimes even absent from school because his condition was declining. This affected his academic achievement, especially during his early illness period.

Although not in all subjects, but in sports subjects Rasya significantly can not demonstrate his ability. Yet this is precisely the subject boys usually get recognition from his peers. Furthermore, because of his low achievement Rasya then begin to develop feelings of failure and missed opportunities to achieve self-esteem.

*"Rasya: Ya, sering diremehkan, diilokkno, gara-gara nggak bisa main sepak bola, dibilang, itu megang bola aja nggak bisa, nggak bisa nendang.*

*Peneliti: Perasaan kamu gimana?*

*Rasya: Sedih tapi cuma diam aja, sedih aja, ngomonge nggak enak.*

*(Rasya: Yeah, often belittled, humiliated, because I can not play football, they say, can not holding the ball, can not kick.*

*Researcher: How's your feeling?*

*Rasya: Sad but just silent, sad, their words hurt my heart.)"*

(Sunday, November 26, 2010)

Suffering from leukemia also disturb the development of Rasya's identity. There is a feeling of shame because he is different compared to his friends. In the end, the attitude of not accepting himself just the way he is would foster negative self-esteem and will indirectly inhibit adjustment with peers (Weitzman, 1984).

For Rasya, his ability to produce something that is productive in accordance with the demands of their environment becomes an important issue. If Rasya believe that his intellectual ability and ability in the field of sport are dissatisfactorily, he could withdraw from the activity. Additionally, Rasya also begin to face challenges from his peers, while he is struggling to establish social relationships. If this is ongoing, it is feared tensions would appear that interferes with the development of his self-esteem as a whole.

To illustrate the influence of leukemia to Rasya's self-esteem as a whole, Figure 4. reveals a hierarchical structure which was adapted from Shavelson (1976).

### Conclusion

Based on the assessments that have been conducted in this study, it can be concluded that chronic diseases such as leukemia can affect every stage of child development depends on the severity of the disease, prognosis, degree of limitation of the child because of illness, presence of genetic history, and frequency of hospitalization. In the end a chronic disease that occurs in child

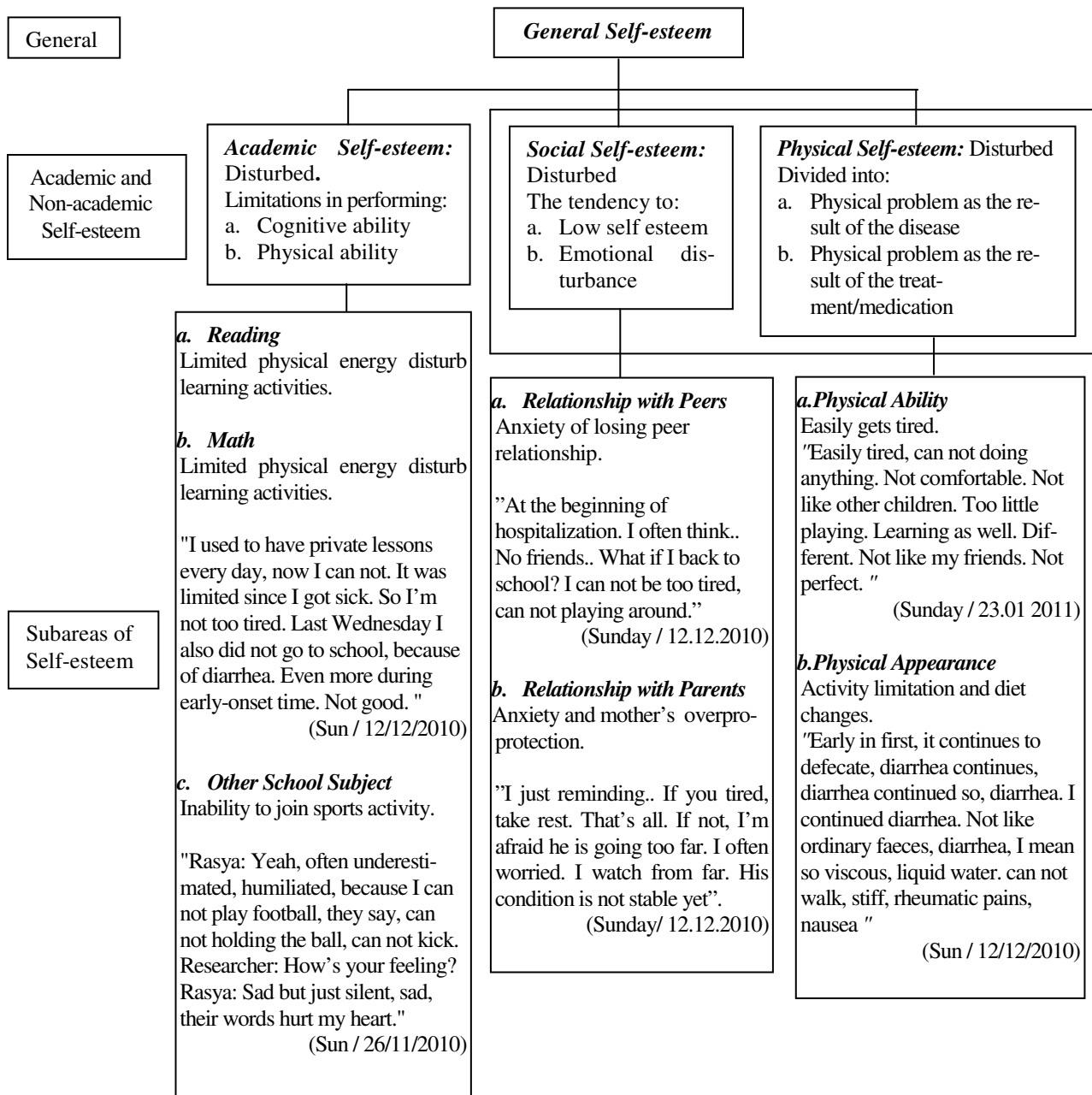


Figure 4. Hierarchical organization model of self-esteem (adapted from Shavelson, 1976) on Rasya

ren can affect psychological well-being of children and the overall quality of life because of the restrictions caused by the disease. This is what happens to Rasya that making him unable to adequately perform his social role and can not have quality of life as high as other children who do not have these symptoms. The low quality of life is not only formed from the disturbed physiological aspects but also because of the negative interpretation within himself. This could bring cognitive distortions for him. If this happened for a long period, it is feared that recovery process will

be hampered, although medically the disease has a good cure rate.

### Limitations

As a single case study it could not be generalized to several similar cases, thereby, it is difficult to make inferences to the population. Limitations on the ability of the first author in concluding in-depth interviews also affect the results of this study, including the process of analysis.

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