

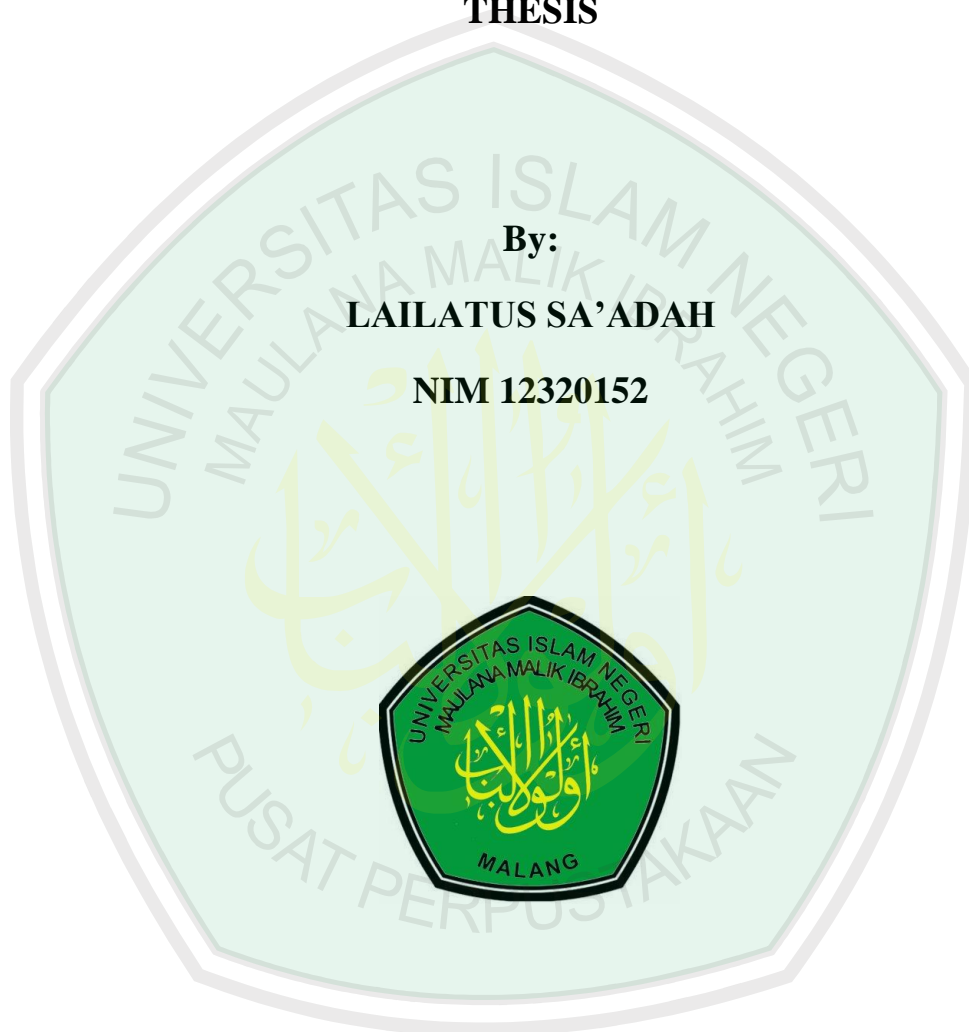
**PARENTING AND PALLIATIVE CARE FOR CHILDREN
WITH CANCER IN JODI PICOULT'S *MY SISTER'S KEEPER***

THESIS

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ENGLISH LETTERS AND LANGUAGE DEPARTMENT

FACULTY OF HUMANITIES

MAULANA MALIK IBRAHIM

STATE ISLAMIC UNIVERSITY, MALANG

2016

**PARENTING AND PALLIATIVE CARE FOR CHILDREN
WITH CANCER IN JODI PICOULT'S *MY SISTER'S KEEPER***

THESIS

Presented to

Maulana Malik Ibrahim State Islamic University Malang

in partial fulfillment of the requirements for the degree of *Sarjana Sastra* (S.S.)

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CERTIFICATE OF THESIS AUTHENTICITY

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certify that the thesis written to fulfill the requirement for the degree of Sarjana Sastra (S.S.) entitled "**Parenting and Palliative Care for Children with Cancer in Jodi Picoult's *My Sister's Keeper***" is truly my original work. I do not incorporate any materials previously written or published by other people, except those one who are indicated in the quotation and bibliography. Due to this fact, I am the only person responsible for the thesis if there is any objection or claim from others.

Malang, June 16, 2016



Lailatus Sa'adah

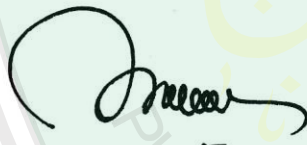
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This is to certify that Sarjana's thesis entitled **"Parenting and Palliative Care for Children with Cancer in Jodi Picoult's *My Sister's Keeper*"** by Lailatus Sa'adah has been approved by the advisor for further approval by the Board of Examiners.

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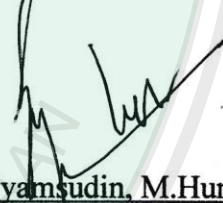


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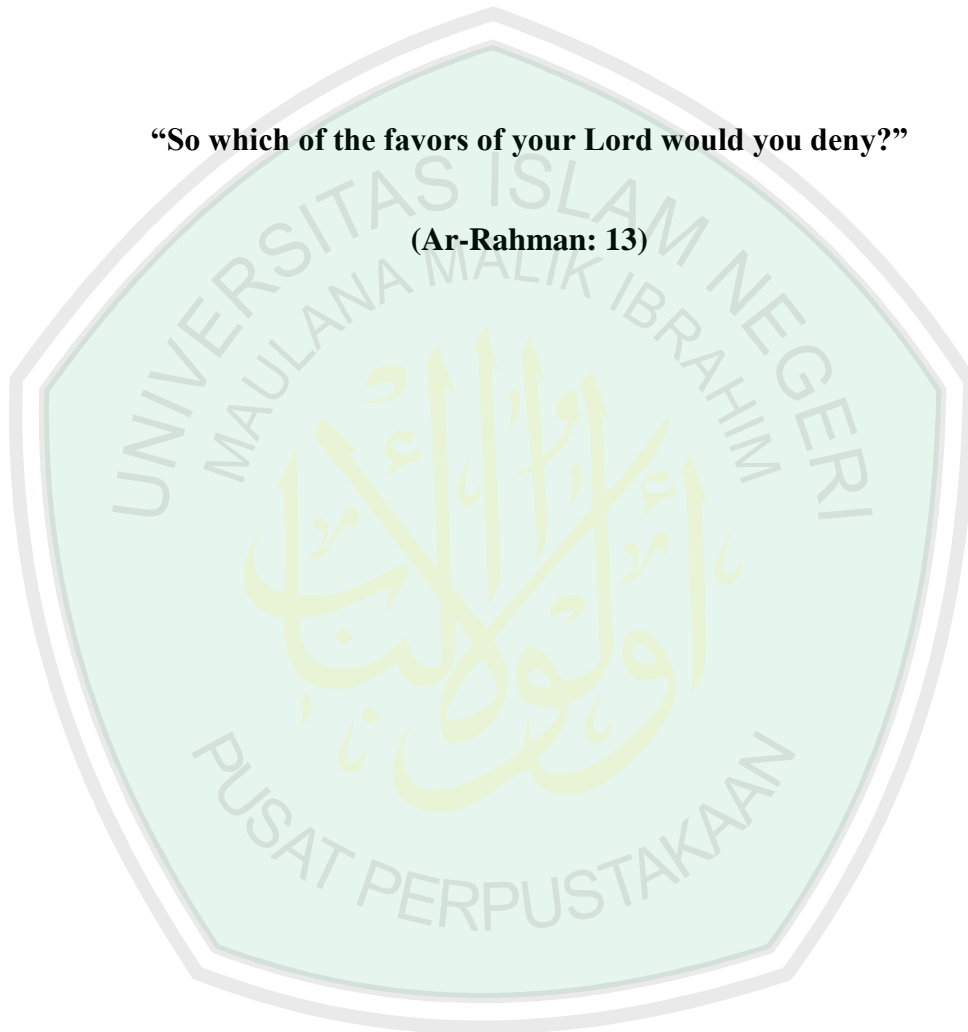
MOTTO

Can a Parent Love too much? Or is too much never enough?

(Picoult, 2004)

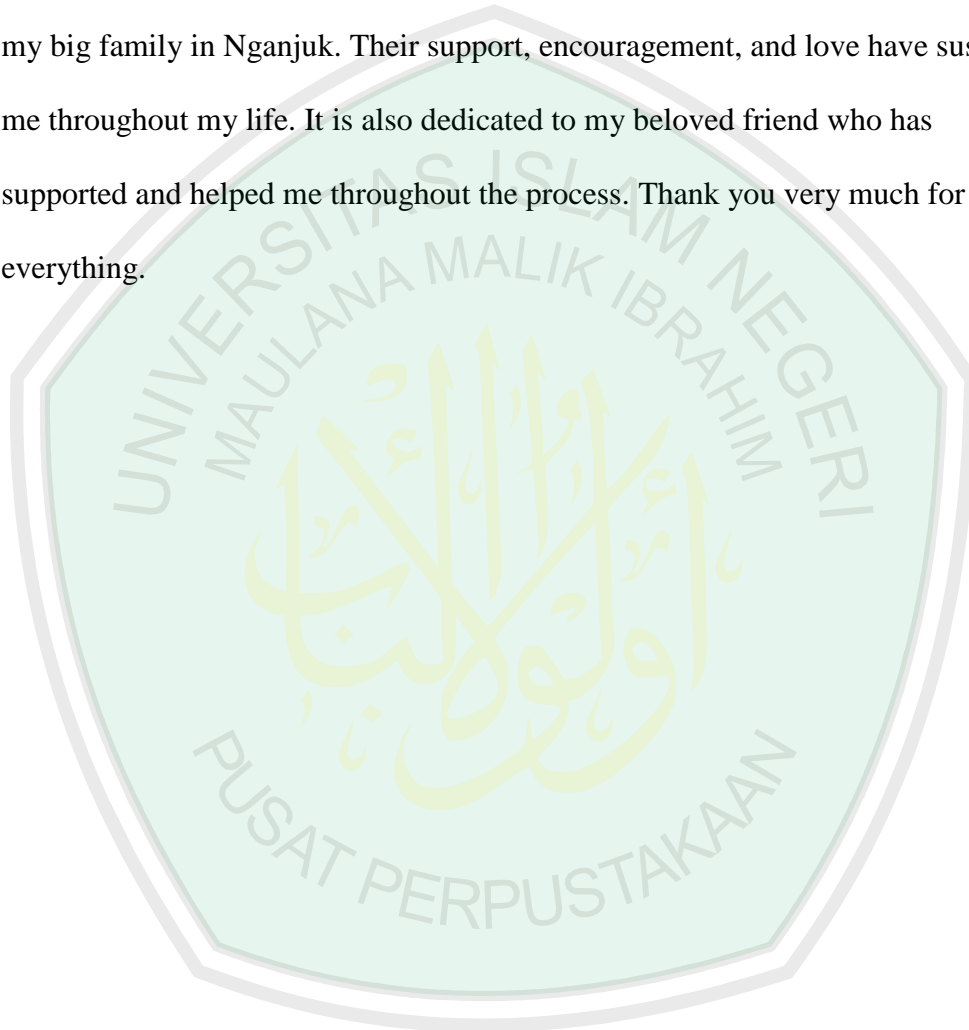
“So which of the favors of your Lord would you deny?”

(Ar-Rahman: 13)



DEDICATION

This thesis is lovingly dedicated to my beloved father (Ahmad Zaini), mother (Tiwi Khoiruroh), sister (Binti Munfaridah) and her warm little family, and also my big family in Nganjuk. Their support, encouragement, and love have sustained me throughout my life. It is also dedicated to my beloved friend who has supported and helped me throughout the process. Thank you very much for everything.



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Secondly, *shalawat* and salaam may always be poured by Allah to our Great Prophet Muhammad SAW who have successful accompanied us go to the truth way and hopefully we are given strength to continue his struggle.

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Undoubtedly, this research has many weaknesses. Therefore, I expect there will be the next researcher who completes the weakness in this study. Furthermore, critics and suggestions are also accepted as the amelioration for the next projects. I hope it will be useful for the readers, especially who learn about parenting strategies for children with cancer.

Malang, June 16, 2016

The Researcher

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ABSTRACT

Sa'adah, Lailatus. 2016. **Parenting and Palliative Care for Children with Cancer in Jodi Picoult's *My Sister's Keeper***. Thesis, English Letters and Language Department, Faculty of Humanities, Maulana Malik Ibrahim State Islamic University, Malang. Advisor: Dr. Hj. Isti'adah, M.A.

Keywords: palliative care, parenting, cancer, leukemia, APL

Parenting is one of the most important things for every parent in raising their children. It happens because parenting can determine children's personality when they are getting older. Because of this condition, the parents are encouraged to give the best parenting for their children. However, the parents cannot give the same parenting for all children. Chronic illness children, such as cancer and leukemia, need different parenting strategies with normal children.

Based on those considerations, the researcher formulates statement of the problems: (1) what parenting strategies for children with cancer are described in Jodi Picoult's *My Sister's Keeper*?, (2) what are the differences between father and mother's parenting strategies for children with cancer in Jodi Picoult's *My Sister's Keeper*?

The researcher uses psychological approach to answer the statement of the problems above, especially focuses on parenting the child with acute lymphoblastic leukemia theory. This theory is proposed by Kars. It is a literary study because it has the purpose to understand and to value author's literary work. The researcher conducts the discussion of literature including description, analysis, and interpretation.

The researcher begins the research with collecting the data. The first step is reading and understanding Jodi Picoult's *My Sister's Keeper* novel. The next step, the researcher chooses the data which deals with statements of the problems. The last step, the researcher simplifies the data and finds the appropriate data which can answer the study's statements of the problems. After finishing collecting the data, the researcher continues to the data analysis. The steps are begun with checking the collected data. The next step is reviewing and identifying the data. The third step is organizing the data. The fourth step is analyzing and interpreting the data. The last step is making conclusion.

The research finding reveals that: (1) the parents show the parenting strategies for children with cancer in the concept of 'being there' which are expressed in six ways; those are trusting relationship, presence, emotional support, advocacy, routines and effacing oneself, (2) a mother and a father have different ways in caring children with cancer in five aspects, those are: processing large amounts of information, sharing or negotiating caregiving, restraining children, adapting to treatment regimens, and communicating.

ABSTRAK

Sa'adah, Lailatus. 2016. Pola asuh dan perawatan paliatif pada anak penderita kanker dalam novel *Penyelamat Kakakku* karya Jodi Picoult. Skripsi, Jurusan Bahasa dan Sastra Inggris, Fakultas Humaniora, UIN Maulana Malik Ibrahim, Malang. Dosen Pembimbing: Dr. Hj. Isti'adah, M.A.

Kata Kunci: perawatan paliatif, pola asuh, kanker, leukemia, APL

Pola asuh adalah salah satu hal yang paling penting bagi orang tua dalam membesarkan anak. Hal ini terjadi karena pola asuh dapat menentukan kepribadian anak ketika mereka tumbuh dewasa. Karena hal tersebut, orang tua menjadi terdorong untuk memberikan pola asuh terbaik untuk anak mereka. Akan tetapi, orang tua tidak bisa menyama ratakan pola asuh bagi semua anak. Anak-anak yang sakit kronis, seperti kanker dan leukemia, membutuhkan pola asuh yang berbeda dengan anak-anak normal.

Berdasarkan pertimbangan di atas, peneliti merumuskan dua rumusan masalah: (1) strategi pola asuh apa yang orang tua gunakan bagi anak penderita kanker yang dideskripsikan dalam novel *Penyelamat Kakakku* karya Jodi Picoult? (2) apa saja perbedaan pola asuh ayah dan ibu untuk anak penderita kanker dalam novel *Penyelamat Kakakku* karya Jodi Picoult?

Peneliti menggunakan pendekatan psikologi untuk menjawab rumusan masalah di atas, terutama fokus pada teori pola asuh anak penderita leukemia limfoblastik akut. Teori ini dikemukakan oleh Kars. Skripsi ini merupakan sebuah kritik kesusasteraan karena bertujuan untuk memahami dan menilai suatu karya sastra. Peneliti membuat diskusi karya yang mencakup deskripsi, analisis, dan interpretasi.

Peneliti memulai penelitian dengan mengumpulkan data. Langkah pertama adalah membaca dan memahami novel *Penyelamat Kakakku* karya Jodi Picoult. Langkah selanjutnya, peneliti memilih data yang berkaitan dengan rumusan masalah. Langkah terakhir, peneliti menyederhanakan dan memilih data yang cocok dengan rumusan masalah. Setelah selesai mengumpulkan data, peneliti melanjutkan penelitian ke analisis data. Langkah pertama, mengecek data yang telah terkumpul. Langkah kedua, meninjau ulang dan mengidentifikasi data yang sudah ada. Langkah ketiga, mengorganisir data. Langkah keempat, menganalisis dan menginterpretasi data. Langkah terakhir, membuat kesimpulan.

Penemuan penelitian menunjukkan bahwa: (1) pola asuh orang tua terhadap anak penderita kanker dilakukan dalam konsep “selalu ada” yang ditunjukkan dalam enam cara; yaitu hubungan saling percaya, kehadiran, dukungan emosional, pembelaan, rutinitas, dan mengabaikan diri sendiri, (2) ibu dan ayah mempunyai cara yang berbeda dalam merawat anak penderita kanker dalam lima aspek, yaitu: proses mendapatkan banyak informasi, berbagi dan bernegosiasi perawatan, mengendalikan anak, beradaptasi pada cara pengobatan, dan komunikasi.

المخلص

السعادة، ليلة ٢٠١٦. الأبوة والأمومة والمطفة الرعاية للأطفال المصابين بالسرطان في الرواية أعمال الإنقاذ شقيقة جودي بيكولت. أطروحة، قسم اللغة الإنجليزية وآدابها، كلية الآداب، جامعة الدولة الإسلامية مولانا مالك إبراهيم مالانج. المشرف: د. الحاج. استعادة، م. ا. كلمات البحث: الرعاية المخففة للآلام، وتربية الأطفال، والسرطان، وسرطان الدم، ا.ف.ل

الأبوة والأمومة هي واحدة من أهم الأشياء للآباء والأمهات في تربية الأطفال. يحدث هذا لأن الأبوة والأمومة يمكن تحديد شخصية الطفل عندما يكبرون في السن. وبسبب هذا، لا يجوز إرغام الوالدين لتقديم أفضل تنشئة أطفالهن. ومع ذلك، يمكن للوالدين لا تتصرف متوسط الأبوة والأمومة لجميع الأطفال. الأطفال الذين يعانون من مرض مزمن، مثل السرطان وسرطان الدم، في حاجة إلى تربية الأطفال يختلف عن الأطفال العاديين.

واستنادا إلى الاعتبارات المذكورة أعلاه، فإننا نقترح اثنين صياغة المشكلة: ١ ما هي الاستراتيجيات الأبوة والأمومة الآباء استخدام لموصوفة الأطفال المصابين بالسرطان في الرواية يعمل الإنقاذ شقيقة جودي بيكولت؟ ٢ أي اختلافات في الأبوة والأمومة الأمهات والآباء للأطفال المصابين بالسرطان في الرواية أعمال الإنقاذ شقيقة جودي بيكولت؟

الباحث باستخدام المنهج النفسي للإجابة على صياغة المشاكل المذكورة أعلاه، مع التركيز بشكل خاص على نظرية الأطفال الأبوة والأمومة مع سرطان الدم الليمفاوي الحاد. وضعت هذه النظرية التي قدمها كارس. هذه الأطروحة هو النقد الأدبي في إطار مساعيه لفهم وتقييم العمل الأدبي. الباحثين في خلق ورقة المناقشة التي تتضمن وصفا والتحليل والتفسير.

بدأ الباحثون الدراسة بجمع البيانات. الخطوة الأولى هي قراءة وفهم رواية أعمال الإنقاذ شقيقة جودي بيكولت. الخطوة التالية، اختار الباحثون بيانات تتعلق صياغة المشكلة. الخطوة النهائية، فإن الباحثين تبسيط وبيانات مختارة يطابق صياغة المشكلة. عند الانتهاء من جمع البيانات، يواصل الباحثون دراسة وتحليل البيانات. الخطوة الأولى، والتحقق من البيانات التي تم جمعها. الخطوة الثانية، مراجعة وتحديد البيانات الموجودة. الخطوة الثالثة، تنظيم البيانات. الخطوة الرابعة وتحليل وتفسير البيانات. الخطوة النهائية، وجعل استنتاجات.

أظهر اكتشاف ما يلي: ١ وسائل لتعليم آباء الأطفال ذوي يتم السرطان في مفهوم "دائما هناك" هو مبين في وهي علاقات الثقة المتبادلة والحضور والدعم العاطفي والدعوة والروتين، وإهمال نفسك، ٢ الأم. ستة طرق والأب طرقا مختلفة لرعاية الأطفال المصابين بالسرطان في خمسة جوانب، وهي: عملية الحصول على الكثير من المعلومات، وتبادل والتفاوض العلاج، السيطرة على الطفل، للتكيف مع الطريقة من العلاج، المضيف وحشية تدعمها برنارد ماركس لإلغاء عملية التلاعب لمستقبل الطبقة الاجتماعية والاتصالات

CHAPTER I

INTRODUCTION

In this chapter, the researcher presents the background of the study, statement of the problems, objectives of the study, scope of the study, significance of the study, research method, and definition of key terms.

1.1. Background of the Study

Parenting is one of the most important things for every parent in raising their children. It is because parenting will give the impacts to the children's physical and mental condition. Therefore, parents hope to give the best parenting for their children. However, parents often feel unsure of themselves and wonder if they are parenting the right way. There is no particular parenting manual that can tell them exactly how to be the best parent (Rabin, 2015).

Parents have different parenting strategies for their children. Parenting strategies are the ways to interact with child or children that create a strong relationship, foster positive behavior, and respond to behavioral problems (Matta, 2012). It affects the way children function as they grow older.

Dina Baumrind is one of psychologists, as well as one of the most well-known researchers on parenting style. In the 1960s, Baumrind developed her Pillar Theory, which draws relationships between basic parenting styles and children's behavior. She proposes three major parenting styles. There are

authoritarian which is too hard, permissive which is too soft, and authoritative which is just right (Cummins, 2016). These kinds of parenting are commonly used in the family.

Parenting normal children and chronic illness children are different. Parenting a child with cancer is very distressing, with parents reporting a sense of loss of control, uncertainty, anxiety, depression, sleep disturbance, and lowered self-esteem (Boman, Lindahl, & Bjork, 2003, cited in Birnie, 2012). It is because parents have to cope with any unexpected condition. Therefore, they have to be extra patience and have a lot of energy in parenting their children with cancer.

The research uses psychological approach. Parenting the child with acute lymphoblastic leukemia is one of psychological theories. It focuses on chronic illness children such as cancer, leukemia, autism, etc. These children need different parenting style with normal children. Besides, they also need more the parents' attention and care.

This research uses parenting the children with acute lymphoblastic leukemia theory proposed by Kars. It is used the core concept of 'being there'. He formulates some expressions of 'being there' used by the parents of acute lymphoblastic leukemia children (Kars, 2012). This theory is used to analyze *My Sister's Keeper* novel written by Jodi Picoult.

Jodi Picoult is an American writer. She is the bestselling author of twenty-three novel. She gets many awards and honors. Some of them are New

England Bookseller Award for Fiction 2003, a lifetime achievement award for mainstream fiction from the Romance Writers of America, *Cosmopolitan* magazine's 'Fearless Fiction' Award 2007, etc (Picoult, 2016). One of her great novels is *My Sister's Keeper* novel published in 2004. It is her eleventh novel.

My Sister's Keeper is a story about family. In this story, there are three children and one of them is an acute leukemia child. The older child is Jesse Fitzgerald, a nineteen-years-old boy. He is a less attention boy since her sister, Kate, was diagnosed as having chronic illness. The second child is Kate Fitzgerald, a sixteen-years-old girl. She gets her first diagnosis as having leukemia when she was three-years-old. The youngest child is Anna Fitzgerald, a thirteen-years-old girl. She is a genetically engineered baby to be match for her sister in order to save her sister's life. Brian and Sara Fitzgerald are the parents of those children. The story tells much the parents' effort to care the palliative children from the first diagnosis until getting well.

In this research, the researcher chooses *My Sister's Keeper* written by Jodi Picoult because of three reasons. First, the novel is one of great novels because it gets some awards such as in ALA Alex Award in 2005, ALA Teens' Top Ten in 2005 and Abraham Lincoln Award in 2006 (Zainal, 2013). Besides, the novel also gets awards in New York Times Bestseller in 2009. It is the first list of paperback mass-market fiction and the second list of paperback trade fiction (The New York Times, 2009).

Second, the novel tells the debatable issue, savior sibling, which is very interesting topic because in some countries it is an uncommon thing. Therefore, from the novel the readers know more about savior sibling and her existence. Third, the novel contains of many good values which can be learnt and practiced. The story tells how to be good children, sibling, and parent; therefore, the good messages can be taken.

Parenting the child with cancer, thus far, has been analyzed in some different objects. The first is a thesis by Marijke C. Kars from University Medical Center Utrecht in 2012 entitled “Parenting and Palliative Care in Paediatric Oncology”. The second is an article by V. Swallow, H. Lambert, S. Santacroce and A. Macfadyen from University of Manchester, Newcastle upon Tyne Hospitals NHS Foundation Trust, Northumbria University, and University of North Carolina at Chapel Hill published in 2011 entitled “Fathers and Mothers Developing Skills in Managing Children’s Long-Term Medical Conditions: How Do Their Qualitative Accounts Compare?” The third is a thesis by J. E M Betman from University of Canterbury in 2006 entitled “Parental Grief When A Child Is Diagnosed with A Life-Threatening Chronic-Illness: The Impact of Gender, Perceptions and Coping Strategies.” The fourth is an article by Clarke-Steffen from De Montfort University in 1998 entitled “Families with Children Diagnosed with Cancer Used Various Strategies to Create a New Normal Routine”.

From the analysis above, the researcher has the same topic to analyze the object. The researcher uses parenting strategies for the child with acute

lymphoblastic leukemia theory. In this case, the researcher tries to make a different analysis. Therefore, the researcher uses the title “Parenting and Palliative Care for Children with cancer in Jodi Picoult’s *My Sister’s Keeper*”.

1.2. Statements of the Problems

Based on the background of the study, the researcher wants to formulate the statement of the problems as following:

1. What parenting strategies for children with cancer are described in Jodi Picoult’s *My Sister’s Keeper*?
2. What are the differences between father and mother’s parenting strategies for children with cancer in Jodi Picoult’s *My Sister’s Keeper*?

1.3. Objectives of the Study

Concerning to the statement of the problems mentioned above, this research is intended to reach the following objectives. Those are:

1. Discovering parenting strategies for children with cancer described in Jodi Picoult’s *My Sister’s Keeper*’s novel.
2. Finding out the differences between a father and a mother in caring a child with cancer.

1.4. Scope of the Study

The scope of the study is the child with cancer. In this study, the researcher uses psychological approach. The researcher limits the study to the parenting strategies for children with cancer and the differences between a father and a mother in caring the children with cancer. The researcher will

only take the data from *My Sister's Keeper* novel written by Jodi Picoult in 2004.

1.5. Significance of the Study

This research has a theoretical and practical significance.

Theoretically, this research is expected to enrich the literary criticism, especially to comprehend parenting the child with acute lymphoblastic leukemia. Practically, the researcher hopes the result of this research can be useful for the next researchers who conduct the similar topic with this research. It can be one of the references that help the next researchers in doing their research by using parenting the child with acute lymphoblastic leukemia theory such as discovering parenting strategies for children with cancer described in Jodi Picoult's *My Sister's Keeper* and finding out the differences between a father and a mother in caring a child with cancer. It is also expected to be continued to the deeper research.

1.6. Research Method

In the research method includes the discussion about research design, data source, data collection, and data analysis.

1.6.1. Research Design

This research is a literary study because it analyzes author's literary work. Literary study, is also called literary criticism, is a study of literary work which has purpose to understand and to value author's

literary work. The researcher conducts the discussion of literature including description, analysis, and interpretation.

In this research, the researcher would like to analyze parenting strategies in *My Sister's Keeper* novel written by Jodi Picoult using psychological approach. Psychological approach is one of approaches used to analyze the literary works. This research focuses on the use of parenting the child with acute lymphoblastic leukemia in analyzing the object.

1.6.2. Data Source

The data are taken from *My Sister's Keeper* novel written by Jodi Picoult. It is published by Washington Square Press 1230 Avenue of the Americas New York, NY 10020 in 2004. It is the eleventh novel written by Jodi Picoult. It consists of 423 pages.

The data are presented in the form of words, phrases, sentences, or discourse of the novel that indicate about the parenting the child with cancer. It will be carefully analyzed to find the needed information and issues. Besides, the data is taken from many sources which are proper with psychological approach especially parenting the child with cancer such as books, journal, theses, etc.

1.6.3. Data Collection

The researcher begins the research with collecting the data. Here, the research takes some steps.

The first step is reading and understanding Jodi Picoult's *My Sister's Keeper* novel. From this step, the researcher finds some general data relating with parenting strategies in the novel in form of paragraphs, sentences, and/or phrases.

In the next step, the researcher chooses the data which deals with statements of the problems. They are discovering parenting strategies for children with cancer described in Jodi Picoult's *My Sister's Keeper* and the differences between a father and a mother in caring a child with cancer.

The last step in data collection is the most important step in the research. In this step, the researcher simplifies the data and finds the appropriate data which can answer the study's statements of the problems.

1.6.4. Data Analysis

After finishing collecting the data, the researcher continues to the data analysis. The data analysis is handled in several steps.

The steps are begun with checking the collected data. This procedure is done to know whether the data which have been collected are right or not. The next step is reviewing and identifying the data. In this step, the researcher reviews and identifies the data which are related to the formulated statement of the problems by marking the statements or paragraph in the novel.

The third step is organizing the data. The researcher organizes and separates the required data. The fourth step is analyzing and interpreting the data. The researcher does deep analysis and interpretation on parenting strategies for children with cancer described in Jodi Picoult's *My Sister's Keeper* and the differences between a father and a mother in caring a child with cancer.

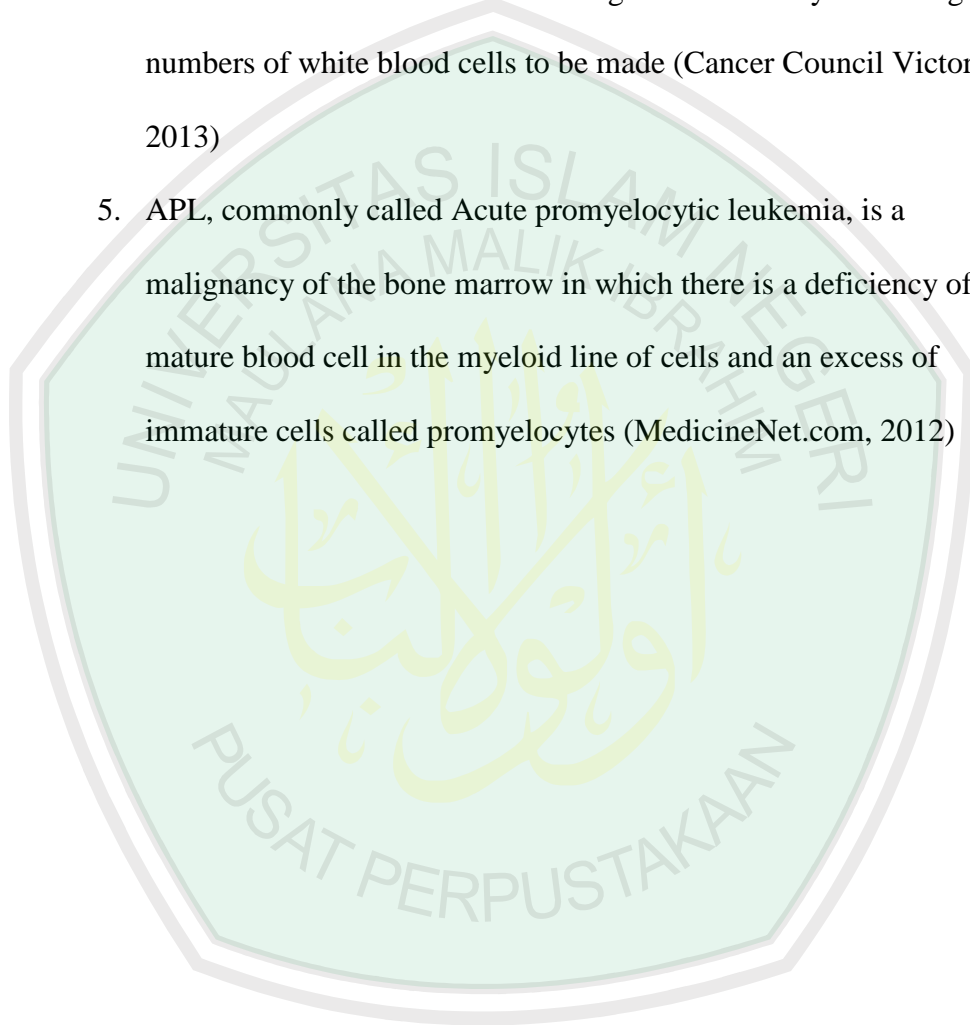
The last step is making conclusion. The researcher concludes and rechecks the data whether it is appropriate to answer the statement of the problems or not. This part is important because after analyzing the data, the researcher has to draw the conclusion. This conclusion must be appropriate to the statement of the problems.

1.7. Definition of Key Terms

To avoid misunderstanding between the researcher and the reader of some important terms or words within this research, the use of specific key terms must be defined.

1. Parenting is the hundreds of activities that parents engage in either with or for their children (Brooks, Markman, & Pithers, 2005)
2. Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization, 2016).

3. Cancer is a broad term for a class of diseases characterized by abnormal cells that grow and invade healthy cells in the body (National Breast Cancer Foundation, 2015)
4. Leukemia is cancer of blood-forming cells. It usually cause large numbers of white blood cells to be made (Cancer Council Victoria, 2013)
5. APL, commonly called Acute promyelocytic leukemia, is a malignancy of the bone marrow in which there is a deficiency of mature blood cell in the myeloid line of cells and an excess of immature cells called promyelocytes (MedicineNet.com, 2012)



CHAPTER II

REVIEW OF THE RELATED LITERATURE

In this chapter, the researcher provides the related literature to the research. In addition, it is to give a brief definition and explanation about palliative care, palliative care for children, parenting the child with acute lymphoblastic leukemia, the differences between fathers and mothers' parenting for child's long term medical conditions, and previous studies.

2.1. Palliative Care

Palliative care is a philosophy of care that evolved from the hospice movement to meet the gaps in care for seriously ill and dying patients (Kars, 2012, p. 10). While, the World Health Organization defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2016).

From the definition above, Kars gives more general meaning about palliative care. He believes that palliative care is a philosophy of care. A philosophy of care is a framework of care goals and values to help you make the best choices for your child and family (National Tay-Sachs & Allied Diseases Association/ NTSAD, 2015). It means that palliative care is care

goals and values for children and/ or family from the hospice movement to get the gaps of serious illness family.

On the other hand, World Health Organization (WHO) defines palliative care in more specific definition. It defines palliative care as an approach that improves the quality of life of patients and their families facing the problem. Improve the quality of life means helping the patients and family to face their problems, physical, psychosocial and spiritual since the first diagnosis, medical treatment until getting well or dying patients.

WHO (2016) defines palliative care as:

- a. “Provides relief from pain and other distressing symptoms;
- b. affirms life and regards dying as a normal process;
- c. intends neither to hasten or postpone death;
- d. integrates the psychological and spiritual aspects of patient care;
- e. offers a support system to help patients live as actively as possible until death;
- f. offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- g. uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- h. will enhance the quality of life, and may also positively influence the course of the illness;
- i. is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy

or radiation therapy, and includes those investigations needed to understand better, and manage, distressing clinical complications.”

2.2. Palliative Care for Children

WHO (2016) believes palliative care for children represents a special, albeit closely related field to adult palliative care. Although palliative care for children and adult are closely related, however, it has a difference. Palliative care for children commonly uses term pediatric. Mandal (2014) argues pediatrics is the branch of medicine dealing with the health and medical care of infants, children, and adolescents from birth up to the age of 18. From the patients above the age of 18 is not called as pediatric. Mandal (2014) believes the word “pediatrics” means “healer of children; they are derived from two Greek words: pais means child, and iatros means doctor or healer.

Pediatrics has some differences from adult medicine. The first is the substantial of the body. The substantial of the infant or child is different psychologically from that of an adult. Children are not a miniature adult. Therefore, the ways to treat children and adults are totally different. Besides, congenital defects, genetic variance, and developmental issues are the great concern for pediatrics. There are also several legal issues in pediatrics. In most jurisdictions, children cannot make their own decisions. The other issues which have to be considered in every pediatric procedure are the issues of guardianship, privacy, legal responsibility and informed consent (Mandal, 2014).

WHO (2016) defines palliative care for children as:

- a. Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- b. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- c. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- d. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- e. It can be provided in tertiary care facilities, in community health centers and even in children's homes.

2.3. Parenting the Child with Acute Lymphoblastic Leukemia

Kars (2012) argues that parenting the child with acute lymphoblastic leukemia uses core concept 'being there'. 'Being there', as it is used by parents, must be understood as: 'I'll be there for you' and 'whatever happens, you can count on me, I will never let you down' (Kars, 2012, p. 37). It means that parents want to be close with the children every time. This concept is very important for all parents because it emerges as a fundamental aspect of parenthood.

'Being there' is one of the evidences that parents love the children much. It shows the hearth of their parenthood and their existence. Kars (2012) states that 'being there' is triggered by this existential crisis at diagnosis and the parental perception of the child suffering from illness and treatment. At the first diagnosed time, parents can imagine their child will die. However, after getting information about treatment, they have a hope for their child to still alive although the child has to get suffering.

'Being there' can be defined as giving care and supports. Parent told us the child appeals to their care and supports (Kars, 2012, p. 37). By 'being there', parents shows their care with their palliative children from the first diagnoses. In addition, they always give support to the child in undergoing the clinical treatments and surgeries.

According to Kars (2012), 'being there' serves two purposes: protection and preservation.

a. Protection

Protection is one of parents' ways to show their love to the children. Parents give protection to their entire child, especially to a chronic illness child. Parents are more selective in choosing friends for their children. The child will get special protection because of their insufferable treatments. Protection means guarding the child against the negative influence and consequences of illness and treatment to improve his/her well-being (Kars, 2012, p. 38). By giving protection, parents hope

their child can undergo surgery and treatments obligingly for their better life.

Kars (2012) argues that additional purposes associated with protection are: creating feelings of safety and comfort, relieving suffering and preventing (the threat of) harm inflicted by others. Parents try hard to create feelings of safety and comfort. Although, in fact, they feel worried and frightened of the surgeries and treatments. However, they have to be strong to make their child stronger. In addition, parents have to relieve suffering to get their child trust. Parents realize that professional do not always place the child first, therefore, they have to prevent harm that other person can inflict.

b. Preservation

Preservation refers to the way parents influence the child's perception of his/her life so the child can better cope with it, thus trying to increase his/her willingness to undergo the treatment to maximize his/her chances for survival (Kars, 2012, p. 39). Parents always try to do best for their children, especially a palliative child. They influence the child's perception of his life. For instance, saying a frightening surgery as an enjoyable thing. They do that thing in order to the child can cope with it.

According to Kars (2012), some common ways parents express 'being there' are trusting relationship, presence, emotional support, advocacy, routines and effacing oneself.

a. A trusting relationship

‘Being there’ takes form in a trusting relationship between child and parent. Parents are well aware of this, actively building, deepening and strengthening the existing trusting relation (Kars, 2012, p. 40). Trusting relationship is much needed in a relationship, especially between parent and child. Parents build this relationship by being honest and clear (tuned into the child’s level of understanding), trying not to harm their child’s trust (Kars, 2012, p. 40).

b. Presence

Parents manage their activities so that at least one of them can be near the child, both literally and figuratively (Kars, 2012, p. 40). It means that one of them is always behind the child during hospitalization and the other cares the other children at home, however, he monitors a child by calling hospital.

Kars (2012) argues that parents want to be available in case their child needs them. In addition to presence availability, physical contact is a powerful manner of expressing ‘being there’. Taking the child on their lap or holding hands allows the child to feel calm and safe.

c. Emotional Support

‘Being there’ is optimized by emotional support. To provide emotional support, insight is needed into the experiences, needs and coping strategies of the child (Kars, 2012, p. 40). For parents, emotional support is a crystal clear that they are the experts (Kars, 2012). They know

their child best because they are aware of the background of his feeling and thinking. They know what make their child frightened and stress and how to cope with it.

d. Advocacy

During treatment, parents develop their parental role and become more experienced and conscious of the differences between themselves and the professionals concerning the interest in and goals for the child (Kars, 2012, p. 41). Parents are more careful in deciding the treatments for their child. However, they are also more experienced with something happen to the child. They know more what the professional has to do if unexpected thing happen.

Particularly, when they notice that the child's suffering is unnecessary or the treatment has shortcomings do they become advocates for the interests of the child (Kars, 2012, p. 41). Because the child is still too young in deciding important thing for his life, parent is the one who advocates him in deciding surgery or treatments.

e. Routines and rituals

'Being there' is also expressed by managing daily living in such a way that the child experiences it as familiar. Daily habits and rituals are continued whenever possible, new comforting rituals are introduced (Kars, 2012, p. 41). Daily habits or routines are better continued, however, as long as it does not burden the child. While, new rituals are introduced in

order to make child enjoying his life, not always think they are sick.

According to Kars (2012), new rituals focus mainly on the transformation of burdensome interventions or experiences into a manner that the child can handle. It is very important to increase child self-confidence.

f. Effacing oneself

‘Being there’ implies that parents efface themselves. Parents told us that they tried to ignore their own fears, worries and needs when it was necessary to support their child (Kars, 2012, p. 41). Child is the priority of the parent. Parent focuses more on how the child can keep life and minimize suffering. They act like strong people in front of the child. Therefore, they ignore themselves for concentrating to the child.

2.4. The Differences between Fathers and Mothers’ Parenting for Child’s Long-term Medical Conditions

Parents’ contributions to condition management are well documented but until recently research tended to focus on mothers as main respondents (Eiser&Havermans 1992; Gallo&Knafl 1998; Knafl & Zoeller 2000; Swallow & Jacoby 2001; Sullivan-Bolyai *et al.* 2006; Aldridge 2008, cited in Swallow et al., 2011, p. 512). This may be because mothers are more often present during clinical consultations, therefore more likely to be approached about research and their accounts used as a proxy for fathers’ accounts (Swallow, 2008, cited in Swallow et al., 2011, p. 512). However, in fact, both of father and mother have their own portion during clinical consultation and health

treatment. Swallow et al. (2011) argue some differences between fathers and mothers in caring palliative children.

a. Processing large amounts of information

When the children get their first diagnosis, their parents have the different ways and responses in order to get a lot of information about the illness. Fathers tend to prefer the bigger picture about the illness. They generally take the long-term view what happen to their children. In other side, mothers focus on the short term in relation to deal with the information provided by professional. Besides, they also attempt to understand about the range of essential treatments the child may needed and their possible impact (Swallow et al., 2011). For mothers, assimilating information from professionals about the best and correct ways in care their children at home and their own actions may give negative result for children is very important thing.

Parents have different role when dealing with large amount of information from the professionals. Mothers tend to become emotional when hearing the information. In contrast, fathers are calmer than mothers (Swallow et al., 2011). Mothers become emotional because they do not believe that their child has been diagnosed suffering a palliative illness and have to do medical treatment. However, fathers are more realistic. When their child are diagnosed, they hear the information from professional calmly and accurately in order to know what the best for the child.

b. Sharing or negotiating caregiving

There was evidence of role divergence with fathers sometimes disengaging from the clinical context when their child was an inpatient to allow time for personal reflection about the situation, but at home the same fathers shared caregiving to support the mother (Swallow et al., 2011, p. 518). Parent has to have a good way in sharing or negotiating caregiving. When a parent has to stay in the hospital for caring a palliative child, the other parent should stay at home and care the other children. However, all participants liked to be included in decision making about clinical management, so when professionals discussed clinical issues, including treatment options, with one parent the information subsequently needed to be relayed by that parent to their partner so they could make a joint decision (Swallow et al., 2011, p. 519).

c. Restraining children

Restraining children is not an easy thing both for children and parents. It could be distressing for children and parents. Mothers and fathers feel it was important for one of them to assist with holding their child. A few mothers restrain their children by holding spontaneously, while the others describe restraining children as central line flushing (Swallow et al., 2011). Some other mothers hold the children after getting instruction from the professionals. They attempt to be strong in restraining the child, although in fact they are shattered looking at the child.

Several fathers spontaneously talked about 'holding' their child for procedures such as urine collection, venepuncture, blood pressure measurement, nasogastric tube insertion, applying local anaesthetic cream and giving medicines, all appearing to regard this as the father's personal responsibility (Swallow et al., 2011, p. 519). They hold the children spontaneously when their children have to do clinical procedures.

d. Adapting to treatment regimens

Parents describe how they attempt to adapt with the new condition, when their children have diagnosis with chronic illness. For instance are the bedroom and the garden shed. Both fathers and mothers think that learning to live with this situation is very distress. Mothers thought adaptation as the worst thing to deal with. However, fathers saw it as an essential thing (Swallow et al., 2011). One of the big problems is adapting in supporting children to take unpleasant medicine. Besides, parents have to have a new behavior changes. It is not an easy thing, but parents have to do it for their children, especially for children with chronic illness.

e. Communicating

Learning to communicate appropriately and effectively with professionals was important to mothers and fathers. Mothers focus on balancing their child's welfare with maintaining good relationships with professionals (Swallow et al., 2011, p. 520). On the other hand, Fathers develop proactive information seeking strategies when communicating

with professionals. Besides, some fathers regain some control in time by reviewing what you know and what will happen next (Swallow et al., 2011).

Parents also need to communicate with other people, except the professionals. Mothers also tend to communicate with relatives and friends about their child condition. Whereas, fathers highlight the importance of communicating with employers to ensure.

2.5. Previous Studies

Parenting strategies for children with cancer, thus far, has been analyzed in some different objects. The first is a thesis by Marijke C. Kars from University Medical Center Utrecht in 2012 entitled “Parenting and Palliative Care in Paediatric Oncology”. In this thesis, Kars uses a grounded theory and interviews 12 mothers and 11 fathers of 12 children with all types of cancer from 0-16 years. The analysis shows that “being there” is described as the core concept. It serves two purposes: protection and preservation. Preservation refers to the way parents influence the child’s perception of his/her life, thus contributing to his/her coping and willingness to undergo treatment, to maximize chances for survival. Six aspects were identified: a trusting relationship, presence, emotional support, advocacy, routines and rituals and effacing oneself.

The second is an article by V. Swallow, H. Lambert, S. Santacroce and A. Macfadyen from University of Manchester, Newcastle upon Tyne

Hospitals NHS Foundation Trust, Northumbria University, and University of North Carolina at Chapel Hill published in 2011 entitled “Fathers and Mothers Developing Skills in Managing Children’s Long-Term Medical Conditions: How Do Their Qualitative Accounts Compare?” In the thesis, the researchers interview biological fathers and mothers of 15 children whose care is managed in specialist unit and analyzed using Framework analysis. The result shows that fathers and mothers made a significant contribution to management and a key theme identified was ‘developing skills’ in: information processing, sharing/negotiating caregiving, restraining children, adapting to treatment regimens and communicating. Although skill development was often a challenging and uncertain process, both fathers and mothers wanted to and did participate in caregiving; they often negotiated this with each other to accommodate caring for other children, paid employment and to provide mutual practical and emotional support.

The third is a thesis by J. E M Betman from University of Canterbury in 2006 entitled “Parental Grief When a Child is Diagnosed with a Life-Threatening Chronic-Illness: The Impact of Gender, Perceptions and Coping Strategies.” In this thesis, Betman used the theories of grief. The participants were recruited through questionnaires randomly sent out by the National Cystic Fibrosis Association. There were 37 mothers and 15 fathers. The result confirmed presence of grief in these parents and indicated that this grief differs for mothers and fathers, with mothers reporting significantly higher level of physical distress. In line with the literature, no gender differences

were found in regards to perception of impact parent felt their child's chronic-illness had had on their life. However, no differences were found amongst the coping strategies used by fathers and mother.

The fourth is an article by Clarke-Steffen from De Montfort University in 1998 entitled "Families with Children Diagnosed with Cancer Used Various Strategies to Create a New Normal Routine". In the thesis, the researcher uses grounded theory to analyze 32 family members (7 mothers, 7 fathers, 6 ill children, and 12 siblings) from 7 families with children diagnosed within the previous 7-30 days with any types of cancer. The result shows that families use 6 strategies to create a new routine. The strategies are managing the flow of information, reorganizing roles, evaluating and shifting priorities, changing future orientation, assigning meaning to the illness, and managing the therapeutic regimen.

From the analysis above, the researcher has the same topic to analyze the object. The researcher uses parenting the child with acute lymphoblastic leukemia theory. In this case, the researcher tries to make a different analysis. The previous studies analyze the parents of children with cancer by doing interviews, while the researcher analyzes the parents by reading comprehensively Jodi Picoult's novel, *My Sister's Keeper*. Therefore, the researcher uses the title "Parenting and Palliative Care for Children with Cancer in Jodi Picoult's *My Sister's Keeper*".

CHAPTER III

ANALYSIS

The first part of this chapter focuses on the form of parenting strategies for children with cancer. It discusses the expressions of 'being there'. Then, the differences between a father and a mother in caring a child with cancer portrayed in the novel. All data are related to Jodi Picoult's *My Sister's Keeper* novel.

3.1. Parenting Strategies for Children with Cancer

Parenting the child with acute lymphoblastic leukemia uses core concept of 'being there'. In Jodi Picoult's *My Sister's Keeper* novel, the concept of 'being there' is used by the parents to express their protection and preservation in several ways. There are trusting relationship, presence, emotional support, advocacy, routines and effacing oneself.

3.1.1. A Trusting Relationship

In *My Sister's Keeper* novel, 'being there' is in the form of a trusting relationship between Sara and Brian Fitzgerald (the parents) and Kate Fitzgerald (the child). Trusting relationship between Sara and Kate is described in the first time Kate has to be drawn her blood.

When the pediatric nurse comes in with her tray, her syringe, her vials, and her rubber tourniquet, Kate starts to scream. I take a deep breath. "Kate, look at me." Her cries bubble down to small hiccups. "It's just going to be a tiny pinch."

"Liar," Jesse whispers under the breath.

Kate relaxes, just the slightest bit.

(My Sister's Keeper: 29)

Kate, three-years-old, thinks that drawing blood using crayons. However, her brother, Jesse, says that drawing blood using great big long needles. He also describes drawing blood is like a shot. Unfortunately, she believes in him. Then, she stares at her mother with a great expectation. She trusts her mother when mother says it uses a small needle. However, she becomes shrieks and fells afraid when the nurse comes. Sara tries to calm her down by saying that it is not sick. She compares drawing blood with a tiny pinch. She says honest thing to the daughter and get Kate's trust. After that, Kate becomes more relaxed in drawing blood.

The other trusting relationship is seen when Kate will undergo pre-transplant regiment.

When the therapist comes to take her into the RT suite, Kate latches on to my leg. "Honey," Brian says, "it's gonna be fine."

She shakes her head and burrows closer. When I crouch down, she throws herself into my arms. "I won't take my eyes off you," I promise.

The room is large, with jungle murals painted on the walls. The linear accelerators are built into the ceiling and a pit below the treatment table, which is little more than a canvas cot covered with a sheet. The radiation therapist places thick lead pieces shaped like beans onto Kate's chest and tells her not to move. She promises that when it's all over, Kate can have a sticker.

I stare at Kate through the protective glass wall.

(My Sister's Keeper: 104-105)

Kate feels worried and scared when the therapist comes. She does not want to go with him. Brian tries to calm her down. However, she is still scared. Then, Sara promises to be close with her. Fortunately, Kate trusts her mother and finally goes to the RT suite with the therapist.

Trusting relationship between the parents and the child is needed. However, parents have to be honest and clear. Besides, they have to do no harm the child's trust. It is like Sara who is truly near with Kate when she undergoes pre-transplant regiment. Therefore, parents have to say the truth in order to get children's trust.

3.1.2. Presence

Parents always want to be close with the child. They want to be the first person who knows when the child's illness is back. It is showed in the data below:

When Kate isn't vomiting, she's crying. I sit on the edge of the bed, holding her half on my lap. The nurses do not have time to nurse. Short-staffed, they administer antiemetics in the IV; they stay for a few moments to see how Kate responds – but inevitably they are called elsewhere to another emergency and the rest falls to us. Brian, who has to leave the room if one of our children gets a stomach virus, is a model of efficiency: wiping her forehead, holding her thin shoulders, dabbing tissues around her mouth.

(My Sister's Keeper: 64-65)

Some days after the doctor diagnosed Kate as an APL (acute promyelocytic leukemia), she vomits many times. Sara holds her half on her lap. Whereas, Brian wipes her forehead, holds her thin shoulders, and

dabs tissues around her mouth. However, sometimes Brian has to leave the room if one of the children gets a stomach virus. When Brian goes, Sara is still behind Kate to take care of her.

Then, the other way to express presence is described in the data below:

“Hey.” Brian touches the crown of my head. He juggles Jesse in his other arm. It is nearly noon, and we are still in pajamas; we never thought to take a change of clothes. “I’m gonna take him down to the cafeteria; get some lunch. You want something?”

I shake my head. Scooting my chair closer to Kate’s bed, I smooth the covers over her legs. I take her hand, and measure it against my own.

Her eyes slit open. For a moment she struggles, unsure of where she is.

(My Sister’s Keeper: 70)

In this case, Sara wants to be close with Kate. She does not want to go anywhere. She wants to be the first person who knows when Kate wakes up or needs something. However, Brian chooses to care of the other child. It is because the child also needs her parents’ attention. Despite of his busy activity, he also thinks of his wife and Kate needs. The presence of at least one of parents is sufficient to take care of the child.

Parents’ presence is also seen on the data below:

Against all odds, Kate survives for ten days on intense transfusions and arsenic therapy. One the eleventh day of her hospitalization, she slips into a coma. I decide I will keep a bedside vigil until she wakes up.

(My Sister’s Keeper: 266)

The other presence is showed by Sara. Sara does not want to leave Kate, although just a moment. When Kate slips into a coma, she decides to do not leave her. Instead, she decides to be bedside her in order to keep vigil if she wakes up. She hopes Kate will see her first when she wakes up from the coma.

The last presence is described when Kate is in end-of-life (EOL) as showed from the data below:

When Brian falls asleep, draped over the foot of the bed, I take Kate's scarred hand between both of mine. I trace the ovals of her nails and remember the first time I painted them, when Brian couldn't believe I'd do that to a one-year-old. Now, twelve years later, I turn over her palm and wish I knew how to read it, or better yet, how to edit that lifeline.

I pull my chair closer to the hospital bed.

(My Sister's Keeper: 271)

When the doctor says that the parents have to say good bye to Kate because of her APL and renal failure, all of family members want to be near with her. Moreover, Brian sleeps behind her and Sara cannot sleep. They want to be always together until Kate does not take a breath again. They want to keep vigil if she wakes up or in contrary.

Parents always want to be close with the child. Nonetheless, they never forget and ignore other children and their duty. Brian still goes work, while Sara guards behind Kate. When the other children need parent's attention, Brian will come to the children and Sara is in the hospital. This managing of activities is very important to separate parent's

attention to the children. Although in fact, parents want to be present behind the chronic illness child.

3.1.3. Emotional Support

Emotional support shows that parents know their child best. It means that they know what makes the child getting distress and afraid. They are the best people in knowing how to cope with her condition.

The first emotional support is described in the data below:

“Kate!” My mother sinks down to the floor, that stupid skirt a cloud around her. “Kate, honey, what hurts?”

Kate hugs a pillow to her stomach, and tears keep streaming down her face. Her pale hair is stuck to her face in damp streaks; her breathing’s too tight.

(My Sister’s Keeper: 11)

For parents, caring a leukemia child in more than ten years is not just a moment. They know the condition of their child very well. When Kate weeps and hugs a pillow to her stomach, Sara becomes very experienced with this condition because it happens not just once or twice. Sara asks what hurts to know how she has to cope with this. She becomes an expert mother in caring and coping with this condition.

The other emotional support can be showed from the data below:

The minute we hit the ER driveway, my mother’s out of the car, hurrying me to get Kate. We are quite a picture walking through the automatic doors, me with Kate bleeding in my arms, and my mother grapping the first nurse who walks by. “She needs platelets,” my mother orders.

(My Sister's Keeper: 97)

When Kate's sick is back, mother knows what she needs very well. Usually, she needs platelets if she vomits the blood. In this case, Sara is very expert in knowing what Kate feels and how to cope with this. Moreover, sometimes she is more expert than the professional because it happens many times.

The last emotional support can be proved from the data below:

It starts when Kate screams in the bathroom. I race upstairs and jimmy the lock to find my nine-years-old standing in front of a toilet splattered with blood. Blood runs down her legs, too, and has soaked through her underpants. This is the calling card for APL – hemorrhage in all sorts of masks and disguises. Kate's had rectal bleeding before, but she was a toddler, she would not remember. "It's all right," I say calmly.

I get a warm washcloth to clean her up, and find a sanitary napkin for her underwear.

(My Sister's Keeper: 224)

Sara becomes experienced with the blood. Kate had rectal bleeding before, when she was a toddler. Therefore, Sara is not frightened with what happen to Kate. She could control her feeling to look strong in front of her child. As the result, Kate becomes calmer in coping with this situation. Therefore, Sara becomes an expert mother in coping with Kate's rectal bleeding.

Emotional support means the parents become more experienced and expert person. Parents know what happen to the child and how to cope

with this very well. Sara becomes more expert when Kate's illness is back. She does not show off her disquiet. Moreover, she acts the thing happens is usual thing, not a dangerous thing. Those are the parents' ways to give their emotional support.

3.1.4. Advocacy

Parents become more experienced when the child's illness is back. In this case, parents always advocate for the goal of the child. Moreover, they decide to do important thing for child's health.

Sara advocates Kate to undergo kidney transplant. It is described in the data below:

... "Can you still do a transplant?" she asks, as if Anna never started her lawsuit, as if it means absolutely nothing.

"Kate's in a pretty grave clinical state," Dr. Chance tells her. "I told you before I don't know if she was strong enough to survive that level of surgery; the odds are even slighter now."

"But if there was a donor," she says, "would you do it?"

(My Sister's Keeper: 97)

Kate is in the stage of the death throes of end-stage kidney disease. Sara insists to do kidney regiment, although the doctor is not too sure Kate is able to survive that level of surgery. For her, less than fifty percent of success possibility is not a big problem because the most important thing is the possibility of Kate's life. Kidney regiment is not a small and easy surgery. However, Sara advocates it in order to Kate is still alive.

The other 'being there' way to show that parents advocate the child is described in the data below:

"It's a very new therapy," Dr. Chance explains. "You get it intravenously, for twenty-five to sixty days. To date, we haven't effected a cure with it. That's not to say it might not happen in the future, but at the moment, we don't even have five-year survival curves – that's how new the drug is. As it is, Kate's exhausted cord blood, allogeneic transplant, radiation, chemo, and ATRA. She's lived ten years past what any of us would have expected."

I find myself nodding already. "Do it," I say, and Brian looks down at his boots.

(My Sister's Keeper: 264)

After hearing doctor's information, Sara decides to do this therapy. It is caused Kate can live more than ten years past with the expectation by undergoing many kinds of treatment regimens. Sara hopes this new therapy would extend Kate's age like before. She advocates Kate completely in doing this therapy.

'Being there' could be expressed by parent's advocacy. Sara always advocates Kate to undergo many kinds of treatments and surgeries. It is in order to lengthen Kate's life. Moreover, small percentage of success possibility of the therapy or treatment is not a matter. When there is a success possibility, she would advocate Kate to do those treatments.

3.1.5. Routines and Rituals

Routines and rituals have to be continued and introduced by the parents. Continuing daily habits and routines should be done in order to

know children's contribution. Besides, parents should introduce new rituals which are comfortable and easy for the child.

The first routine is showed when Kate is still three-years-old. It is proved from the data below:

Kate sits in her car seat, eating animal crackers. "Play," she commands.

In the rearview mirror, her face is luminous. Objects are closer than they appear. I watch her hold up the first cracker. "What does the tiger says?" I manage "Rrroar." She bites off its head, then waves another cracker.

"What does the elephant says?"

Kate giggles, then trumpets through her nose.

(My Sister's Keeper: 35)

Before Kate having diagnoses as APL, she usually plays the sounds of animal with her mother. This activity is continued although she is diagnosed as an APL child. Sara tries to act like usual and do their routines as best as she could do. As the result, in this situation, Kate looks happy playing this game.

Sometimes, new ritual has to be introduced for the child's health. It is described in the data below:

Since Day Six, when Kate's blood cell and neutrophil counts began to plummet, she has been in reserve isolation. Any germ in the world might kill her now; for this reason, the world is made to keep its distance. Visitors to her room are restricted, and those who are allowed in look like spacemen, gowned, and masked. Kate has to read picture books while wearing rubber gloves. No plants or flowers are permitted, because they carry bacteria that could kill her. Any toy given to her must be scrubbed down with antiseptic solution first. She sleeps with her teddy bear,

sealed in a Ziploc bag, which rustles all night and sometimes wakes her up.

(My Sister's Keeper: 105)

New rituals are introduced for Kate's health. After undergoing transplant regiment, she has been in reserve isolation. Before entering to her room, the visitors have to wear special attributes. It is like spacemen, gowned, and masked. Moreover, when Kate wants to read picture books, she has to wear rubber gloves. In addition, Sara has to scrub down with antiseptic first before giving the toys to Kate.

In the different situation, parents try to celebrate Thanksgiving Day when Kate's condition is better as described in the data below:

One Thanksgiving when Kate was not in the hospital, we actually pretended to be a regular family. We watched the parade on TV, where a giant balloon fell prey to a freak wind and wound up wrapped around a NYC traffic light. We made our own gravy. My mother brought the turkey's wishbone out to the table, and we fought over who would be granted the right to snap it. Kate and I were given the honors. Before I got a good trip, my mother leaned close and whispered into my ears, "You know what to wish for." So I shut my eyes tight and thought hard of remission for Kate, even though I had been planning to ask for a personal CD player, and got a nasty satisfaction out of the fact that I did not win the hug-of-war.

After we ate, my father took us outside for a game of two-one-two touch football while my mother was washing the dishes.

(My Sister's Keeper: 136-137)

Fitzgerald family cannot celebrate Thanksgiving Day every year because sometimes Kate condition is not well. It is caused they have to

take care of her in the hospital. Fortunately, in this Thanksgiving Day, Kate is not in the hospital. Therefore, the parents try hard to celebrate it. They do the celebration rituals like others families. It is because parents hope to celebrate it well, while Kate could show her contribution to the rituals. They watch York City Macy's parade on TV. They cook and eat gravy and turkey which are some kinds of traditional foods in Thanksgiving (Ghose, 2012). Turkey is one of harvests in America. This day is celebrated in order to gratitude to God for His blessing in getting a lot of harvests (Plimoth Plantation, 2016). The breaking of the turkey's wishbone is also the part of this celebration. Besides, they also play an easy nice game. Therefore, Kate could show her contribution in celebrating Thanksgiving. Thanksgiving is gathering together in grateful appreciation with friends and family in a deeply meaningful and comforting annual ritual to most Americans (Plimoth Plantation, 2016). Fitzgerald family expresses their gratitude is at the heart of all this feasting, prayerful thanks, recreation, and nostalgia.

The other routine is when Kate celebrates her birthday party. It is a kind of continuing the routines.

Downstairs, there are twenty-five second-graders, a cake in the shape of a unicorn, and a local college kid hired to make swords and bears and crowns out of balloons. Kate opens her presents – necklaces made of glittery beads, craft kits, Barbie paraphernalia. She saves the biggest box for last – the one Brian and I have gotten her. Inside a glass bowl swims a fantail goldfish.

(My Sister's Keeper: 164)

Normally, child wants a perfect birthday party which celebrates with her friends. Likewise Kate, she also hopes it. To realize her hope, Sara and Brian prepare a small nice party. The decoration is from the balloons in the form of swords, bears, and crowns. This is safe and interesting for the kids. Therefore, Kate looks so happy in celebrating her birthday party.

The next routines is playing ball with the family. It could be proved from the quotation below:

Laughter rises like steam, swims through the windows. After three days of a torrential downpour, the kids are delighted to be outside, kicking around a soccer ball with Brian. When life is normal, it is so normal.

(My Sister's Keeper: 175-176)

Brian asks his children to play soccer ball to spend their time together. They play it easily and safely because they just kick the ball slowly. Nonetheless, they look enjoying much of their togetherness normally. They could play simple game together in the spare time is a kind of simple routines they continue in doing.

Sometimes, parents ask the children to go outside for eating, however, with new adaptation. It is proved in the data below:

Twenty-one days after the bone marrow transplant, Kate's white cell counts begin to rise, proof of engraftment. To celebrate, Brian insists that he is taking me out to dinner. He arranges for a private-duty nurse for Kate, makes

reservations at XO Café, and even brings me a black dress from my closet.

(My Sister's Keeper: 234-235)

After knowing that Kate is getting well, Brian wants to celebrate it. He asks Sara and the children to go outside for dinner. Moreover, for Kate's safety, he hires a private-duty nurse. It is to keep vigil if a bad thing happens to Kate, the professional is behind her. Nevertheless, they enjoy their dinner outside because they can meet and interact with other people, not just nurses and doctors.

There is a time for introducing new rituals in daily life for Kate's health.

At home, we all wear masks so that Kate doesn't have to. I find myself checking her fingernails while she brushes her teeth or pours cereal, to see if the dark ridges made by the chemo have disappeared – a sure sign of the bone marrow transplant's success. Twice a day I give Kate growth factors shots in the tight, a necessity until her neutrophil count tops one thousand. At that point, the marrow will be reseeded itself.

(My Sister's Keeper: 238)

There are two new rituals from the paragraph above. The first ritual is everyone has to wear mask, so that Kate does not have to do it. Sometimes, the other family members have to do new rituals for decreasing Kate's burden. The second ritual is to give growth factors shots. Sara is the person who gives the shots to Kate twice a day. She has to do this ritual until Kate neutrophil count tops one thousand.

The last of rituals is proved from the data below:

We have been shopping for a prom dress for hours. Kate has only two days to prepare for this dance, and it has become an obsession: what she will wear, how she will do her makeup, if the band is going to play anything remotely decent. Her hair, of course, is not an issue; after chemo she lost it all. She hates wigs – they feel like bugs on her scalp, she says – but she’s too self-conscious to go commando. Today, she was wrapped a batik scarf around her head, like a proud, pale African queen.

(My Sister’s Keeper: 315-316)

It is the first time Kate is going to go to the party with a boy. She has to prepare many things before going there. Like other girls, for Kate, go shopping is a must ritual before coming to the part. Sara and Anna accompany her to go shopping. They give Kate suggestion for her best appearance in the party. Besides choosing a dress, Kate has to think of her makeup and hair. These rituals commonly done by normal people, however, for Kate, she chooses a scarf to cover her head.

Parents should manage daily routines and rituals to be continued so that child could handle it. Brian and Sara try to change the daily habits to be simple one so that Kate could contribute to it. Sometimes, new rituals need to be done, especially for Kate’s health. It is caused Kate’s health is the most important thing.

3.1.6. Effacing Oneself

Parents always think that children are the priority. Moreover, sometimes they ignore themselves to support their children. They efface their own feelings, such as fears and worries, and also needs.

Effacing oneself is described in the quotation below:

“Hey.” Brian touches the crown of my head. He juggles Jesse in his other arm. It is nearly noon, and we are still in pajamas; we never thought to take a change of clothes. “I’m gonna take him down to the cafeteria; get some lunch. You want something?”

I shake my head.

(My Sister’s Keeper: 70)

Sara and Brian efface their own needs. They do not think to change the pajamas with other clothes. They just think of to be close with Kate to support her. Moreover, Sara wants to eat nothing for lunch. Whereas, eating is very important need to support her health and energy. However, she ignores her own needs to support her daughter.

Sara ignores her illness to support Kate as described in the quotation below:

Day Zero of Kate’s pre-transplant regimen starts the morning after Anna is born. I come down from the maternity ward and meet Kate in Radiology. We are both wearing yellow isolation gowns, and this make her laugh. “Mommy,” she says, “we match.”

(My Sister’s Keeper: 104)

One day before the day of Kate's pre-transplant regimen, Sara bears Anna in the same hospital. However, she ignores her illness after giving birth Anna. She comes to Radiology in order to meet with Kate. She wants to give support to Kate before she undergoes surgery.

The last effacing oneself is proved from the data below:

"I'm hungry." He nods at the fruit in my hands. "And you're already got a patient."

"For all you know that someone else's. God knows what it's doped up with."

Suddenly Dr. Chance turns the corner and approaches us. Donna, an oncology nurse, walks behind him, brandishing an IV bag filled with crimson liquid. "Drum roll," he says.

I put down my orange, follow them into the anteroom, and suit up so that I can come within ten feet of my daughter.

(My Sister's Keeper: 106)

Six days after transplant regimen day, Kate has been in reverse isolation. It is because her white blood cell and neutrophil counts began to plummet. She needs growth factor shots and this duty fall to Sara. Sara is energetic in practice giving injection to an orange. Moreover, when the doctor and the nurse come to Kate in hurry, she follows them into the anteroom. She ignores herself when she feels hungry. She wants to be near with Kate to know what happens to her daughter and also to support her.

Sometimes, parent effaces their own feelings and also needs for the child. They want to look strong in front of the child, although in fact, they also feel worried and fearful. Sara and Brian want to be near with Kate in order to support her undergoing surgeries and treatments.

3.2. The Differences between a Father and a Mother's Parenting

Strategies for Children with Cancer

Parents are the first people who want to be close with the child when she has to do serious thing, such as treatment and surgery. They want to know what happen to the child and what they can do for her. They take care of the child the best of they could do. However, father and mother have different ways in caring a child with cancer. Besides, they also give care and support to the child, although it is in different portion. Nonetheless, both of them always love and take care of her. In Jodi Picoult's *My Sister's Keeper*, there are some evidences which prove the different ways between a father and a mother in caring a child with cancer.

3.2.1. Processing Large Amount of Information

Parents will get a lot of information about the child's illness such as about the treatments, therapies, and surgeries and its consequences to the child. From the first diagnoses, parents often communicate with the professional, such as the doctors and oncology nurses. However, the processing large amount of information between father and mother is totally different.

Father tends to prefer the bigger picture about the child illness. It is proved from the data below:

... "The thing about leukemia," one nurse explains, "is that we haven't even inserted a needle for the first treatment when we're already thinking three treatments down the line. This particular illness carries a pretty poor prognosis,

so we need to be thinking ahead to what happens next. What makes APL a little trickier is that it's a chemoresistant disease."

"What's that?" Brian asks.

"Normally, with myelogenous leukemias, as long as the organs hold up, you can potentially reinduce the patient into remission every time there's a relapse. ..."

"Are you saying," Brian swallows. "Are you saying she's going to die?"

"I'm saying there are no guarantees."

(My Sister's Keeper: 61-62)

Father wants to know all things about the child's illness. He wants to know what will happen to Kate, how Kate can live, and how to cope with it. All of those information fall like bombs to him. Therefore, he does not want to hear any information more about his child's illness.

In addition, generally father takes the long term view what happen to the child. It can be showed from the data below:

When Kate was born, I used to imagine how beautiful she would be on her wedding day. Then she was diagnosed with APL, and instead, I'd imagine her walking across a stage to get her high school diploma. When she relapsed, all this went out the window: I pictured her making it into her fifth birthday party. Nowadays, I don't have expectations, and this way she beats them all.

(My Sister's Keeper: 43)

Father wants to know what will happen to his daughter in the future. He imagines Kate's wedding someday. When Kate is diagnosed with APL, he hopes she can continue her school until high school diploma; moreover, she graduates in that school. However, when she relapses, he

has to be back to the reality. He just hopes Kate could celebrate her fifth birthday party.

In contrary, mother focuses on the short term in relation to deal with the information and the impacts of treatment to the child. It is described in the quotation below:

The nurse hangs the infusion bags on the IV pole and smooths Kate's hair. "Will she feel it?" I ask.

"Nope. Hey, Kate, look here." She points to the bag of Danurobicin, covered with a dark bag to protect it from light. Spotting it are brightly colored stickers she's helped Kate make while we were waiting. I saw one teenager with a Post-it on his: Jesus saves. Chemo scores.

(My Sister's Keeper: 64)

Sara tends to prefer on the short term information about her daughter. She focuses more on what happen here and now. When her daughter has to do surgery or clinical treatment, she is more worried about the impact of treatment to the child. Besides, she also thinks of her daughter's feeling. Moreover, she feels delighted if the daughter is still alive.

Parents also have role divergence when dealing with large amount of information provided by professionals. The first evidence can be showed from the quotation below:

"Okay," Brian says. He claps his hands together, as if he is gearing up for a football game. "Okay."

Kate pulls her head away from my skirt. Her cheeks are flushed, her expression wary.

This is a mistake. This is someone else's unfortunate vial of blood that the doctor has analyzed. Look at my child, at the shine of her flyaway curls and the butterfly flight of her smile – this is not the face of someone dying by degrees.

(My Sister's Keeper: 34)

This part is taken from Sara's point of view. After hearing the professional's explanation and suggestion about Kate's illness, Brian immediately decides to agree with the suggestion in doing the next clinical treatment. He thinks of her daughter's health. However, Sara still does not believe in the doctor diagnoses. She hopes the doctor gives the wrong diagnoses and a miracle comes to her daughter.

The other evidence of Sara's respond is described in the data below:

He is talking about my little girl as if she were some kind of machine: a car with a faulty carburetor, a plane whose landing gear is stuck. Rather than face this, I turn away just in time to see one of the misbegotten leaves on the plant make its suicide plunge to the carpet. Without an explanation I get to my feet and pick up the planter. I walk out of Dr. Chance's office, past the receptionist and the other shell-shocked parents waiting with their sick children. At the first trash receptacle I find, I dump the plant and all its desiccated soil.

(My Sister's Keeper: 66)

Sara does not want to hear the other information about her daughter from the doctor anymore. All of that information makes her be afraid. She does not believe in the fact of Kate's condition. She does not have any braveness to face this all.

Brian and Sara are different in responding the process large amounts of information from the professional. Brian tends to prefer the bigger picture of the illness and take long-term view to the daughter. He thinks of her daughter in the future. In other side, Sara tends to prefer short-term in dealing with the information about her daughter. She prefers to think of here and now about Kate.

3.2.2. Sharing or Negotiating Caregiving.

Parents usually share caregiving to a child because both of them cannot stay and take care of her together. When a father has to go outside, a mother will take care of the children. On the other situation, a father will take care of other children when a mother takes care of a palliative child.

The first evidence is described in the data below:

When Kate isn't vomiting, she's crying. I sit on the edge of the bed, holding her half on my lap. The nurses do not have time to nurse. Short-staffed, they administer antiemetics in the IV; they stay for a few moments to see how Kate responds – but inevitably they are called elsewhere to another emergency and the rest falls to us. Brian, who has to leave the room if one of our children gets a stomach virus, is a model of efficiency: wiping her forehead, holding her thin shoulders, dabbing tissues around her mouth. "You can get through this," he murmurs to her each time she spits up, but he may only be talking to himself.

And I, too, am surprising myself. With grim resolve I make a ballet out of rinsing the emesis basin and bringing it back.

(My Sister's Keeper: 64-65)

Some days after the doctor diagnosed Kate as an APL, she vomits many times. When knowing this condition, Sara and Brian take care of

Kate the best they can do. However, sometimes one of them cannot be behind her all the time. If one of the children needs something, Brian will leave the room. While, Sara is still take care of Kate. After that, he goes back to the room to take care of Kate with Sara.

Sharing and negotiating caregiving is also can be showed from the quotation below:

... “We’re going to the ER,” I announce, although Brian is already wrapping Kate’s blankets around her and lifting her out of her crib. We bustle her to the car and start the engine and then remember that we cannot leave Jesse home alone. “You go with her,” Brian answers, reading my mind. “I’ll stay here.” But he doesn’t take his eyes off Kate.

(My Sister’s Keeper: 68-69)

Sometimes when Kate’s illness is back, one of the parents cannot go to the hospital with her. It is because parents have to share taking care of the children. They cannot leave their child at home without any attention. However, they do not want to bring their child to the hospital in the middle night while he is in a deep sleep. If this situation comes, the parents have to negotiate caregiving. Brian chooses to stay at home with other children. Then, he asks Sara to go to the hospital with Kate in order to accompany her undergoing the treatment.

The next sharing and negotiating caregiving is described in the data below:

My father calls at eleven o’clock to ask if I want him to come get me. “Mom’s going to stay at the hospital,” he

explains. "But if you don't want to be alone in the house, you can sleep at the station."

(My Sister's Keeper: 131)

These sentences show that Brian is the one who is very flexible. He tries to keep working and caregiving with Anna. In other side, Sara always regards Kate as the priority. She never leaves Kate. Moreover, when Kate is at the hospital, she would not go home. Therefore, caregiving for other children is Brian's duty. It is Sara and Brian deal to give care for all children. Sara has a duty to take care of Kate because she can stay behind her every time. While, Brian has to go work for paying Kate treatments and take care of the children.

The other sharing and negotiating caregiving can be showed from the quotation below:

One day my sister arrives unannounced, and with Brian's permission, spirits me away to a penthouse suite at the Ritz Carlton in Boston. "We can do anything you want," she tells me.

(My Sister's Keeper: 174)

Human needs entertainment. If they focus on one thing much, they might get distress. Usually, Sara is always close with Kate because she wants to know everything about her daughter. However, when her sister asks her to go outside, Brian takes Sara's place. He gives her wife permission to go outside. He chooses to stay behind Kate to support her. In this case, parents negotiate caregiving for a palliative child. Therefore, at least one of parents has to care the child.

The next evidence of sharing and negotiating caregiving can be showed from the data below:

Finally Brian leans down, kisses Kate's forehead. "Baby, you get a good night's sleep." As Anna and Jesse slip into the hall, he kisses me good-bye too. "Call me," he whispers.

And then, when they are all gone, I sit down beside my daughter. Her arms are so thin I can see the bones shifting as she moves; her eyes seem older than mine.

(My Sister's Keeper: 395)

When Kate hospitalizes, Sara always sleeps behind her in the hospital. Caregiving for Kate is Sara duty because she knows her very well. In contrast, Brian leaves hospital with the other children because they also need parent's care. Nevertheless, he never forgets Kate. He waits for the calling from hospital if a serious situation happens to Kate. When he gets the calling, he would come to the hospital immediately with the other children.

The last sharing and negotiating caregiving is described in the quotation below:

My beeper goes off just as Kate starts another course of dialysis. An MVA, two cars, with PI – a motor vehicle accident with injuries. "They need me," I tell Sara. "You'll be okay?"

(My Sister's Keeper: 413)

Brian gets a calling from his station to go work because a serious thing has to be done. Usually, Brian and Sara always wait Kate when she get course of dialysis. They want to give support to her while seeing the

process of treatment. However, when Brian has to go because of his work, Sara would wait for Kate.

Sharing and negotiating caregiving is very important between father and mother. Commonly, father cannot stay behind the child every time. Brian has to divide his time into going to work, caregiving Kate, and caregiving other children, Jesse and Anna. On the contrary, Sara focuses on taking care of Kate. She is always close with Kate in the hospital. Nevertheless, when Kate has to undergo surgery or treatment, both of them always wait her in order to give her support.

3.2.3. Restraining children

Restraining children is needed to ensure the child's treatment. Although it would be distressing for both parent and children, but they have to do it.

Sara's way to restrain her daughter is showed in the quotation below:

Kate relaxes, just the slightest bit. The nurse lays her down on the examination table and asks me to hold down her shoulders. I watch the needle break the white skin of her arm; I hear the sudden scream – but there isn't any blood flowing.

(My Sister's Keeper: 29)

The first time Kate is drawn some blood, Sara looks worried to her condition. She does not think of the way to restrain her until the nurse asks

her to hold Kate's shoulders. She does not have initiative to hold her in order to ensure the treatment.

On the contrary, Brian spontaneously holds the child. It is proved from the data below:

Brian brings Jesse to the hospital for his blood test: a simple finger stick. He needed to be restrained by Brian and two male residents; he screams down the hospital.

(My Sister's Keeper: 65)

Brian thinks that holding the child is father's personal responsibility. He spontaneously holds the child to clinical procedure when he does not go work. He brings Jesse to the hospital in order to know whether his blood is same with Kate or not. He needs other nurses to hold Jesse in his blood test. For father, holding the children is a way to restrain them.

The difference between Brian and Sara in restraining the child is showed from the quotation below:

When the therapist comes to take her into the RT suite, Kate latches on to my leg. "Honey," Brian says, "it's gonna be fine."

She shakes her head and burrows closer. When I crouch down, she throws herself into my arms. "I won't take my eyes off you," I promise.

(My Sister's Keeper: 104-105)

The day of pre-transplant regimen, Kate does not want to go to the radiology room. She feels so afraid with the therapist. Then, Brian tries to

make her calm by saying that everything will be okay. However, Kate does not believe in him, she still feels worried. Then, Sara makes her calm by giving hug to her. In addition, Sara also gives support to her by giving promise to be always near with him. Thus, she is successful in restraining Kate.

The other difference is described in the data below:

The door opens, and the hematologist comes in. "Hello, gang. Mom, you want to hold her on your lap?"

So I crawl onto the table and settle Anna in my arms. Brian gets stationed behind us, so that he can grab Anna's shoulder and elbow and keep it immobilized. "You ready?" the doctor asks Anna, who is still smiling.

(My Sister's Keeper: 170)

To ensure the procedure, Sara and Brian hold Kate together.

However, Sara hold her after the doctor asks to her. It means she does not do that spontaneously. In contrast, Brian holds her spontaneously when he knows her wife is ready to take Anna on her lap. Both of them hold Anna because she never does blood test before, they prepare her reaction after drawing blood. However, she thrashes powerfully until the nurses help them.

From the data above, it shows that a father and a mother have different ways to restrain the children. Mother does not hold the child spontaneously, but she will do it when the professional asks her. On the contrary, father holds the child spontaneously when he knows that he has

to do it. However, father is not as expert as mother in making the child calm before doing any procedures.

3.2.4. Adapting to Treatment Regimens

After the child is diagnosed with APL, parents have to adapt with many things, such as treatment regimens. Adaptation is not an easy thing for parents and also the child. The biggest problem is adaptation in giving the child support to take unpleasant medicine. However, they have to do it for the child's life. Nonetheless, father and mother are different in adapting to treatment regimens.

Mother's first adapting to the treatment regimens is described in the quotation below:

Brian and I sit outside the anteroom, waiting. While Kate sleeps, I practice giving injections to an orange. After the transplant Kate will need growth factor shots, and the core will fall to me. I prick the syringe under the thick skin of the fruit, until I feel the soft give of tissue underneath. The drug I will be giving is subcutaneous, injected just under the skin. I need to make sure the angle is right and that I am giving the proper amount of pressure. The speed with which you push the needle down can cause more or less pain. The orange, of course, doesn't cry when I make a mistake. But the nurses still tell me that injecting Kate won't feel much different.

(My Sister's Keeper: 106)

Sara has to give growth factor shots to Kate after she undergoes transplant. However before she does it to her, she decides to practice giving some injections to an orange. She tries to give injection in the right angle and on the proper amount of pressure. It is because she does not

want to hurt Kate. She thinks that it is a strenuous duty. But she has to do it for her daughter.

The other mother's adaptation to treatment regimens is showed in the data below:

In preparation for the bone marrow harvest, I have to give Anna ongoing growth factor shots, just like I once gave Kate after her initial cord blood transplant. The intent is to hyper-pack Anna's marrow, so that when it is time to withdraw the cells, there will be plenty for Kate.

Anna has been told this, too, but all she knows is that twice a day, her mother has to give her a shot.

We use EMLA cream, a topical anesthetic. The cream is supposed to keep her from feeling the prick of the needle, but she still yells. I wonder if it hurts as much as having your six-years-old stare you in the eye and say she hates you.

(My Sister's Keeper: 226)

It is same with previous evidence. The difference is the object of injection. In this situation, Sara give growth factor shots to Anna, of course, in order to Kate's health. However, she could get distress when she knows her daughter feels painful of her shot. Therefore, she tries hard to inject her accurately, so that she has not to inject her in the other place anymore.

After Kate does chemo, Sara has to adapt to the effect of it to her daughter.

She turns to me and tries to speak, but coughs up phlegm instead. "Drown," she chokes out.

Raising the suction tube she's clutching in her hand, I clear out her mouth and throat. "I'll do it while you rest," I promise, and that is how I come to breathe for her.

(My Sister's Keeper: 229)

The chemo has made Kate throw up thirty-two times. It means that Sara has to drown it every time. Actually, it is hard for her to look at her daughter get the effect of unpleasant medicine. However, she tries to look strong in adapting to this condition for Kate. She hopes her daughter would strong in undergoing this condition.

In addition, Sara tries to adapt to behavior changes. It is showed in the data below:

"Where do you think we'll go out?"

I think of Brian, who has always said that Kate can date ... when she's forty. "Let's take one step at a time," I suggest. But inside, I am singing.

(My Sister's Keeper: 309)

Sara is a flexible mother. She knows Kate seems falling in love with Taylor. When Kate wants to go date with him, she remembers her husband's prohibition. He does not give Kate permission to date before forty. But she gives her permission because it is unbelievable thing to see her dating. She feels happy when she looks her daughter could fall in love with someone. It is a miracle for her looking at her daughter until in that age, therefore, she decides to give her permission.

Father sees adaptation as an essential. In this case, Brian tries to adapt to the effect of treatment regimens to Kate.

Twenty-one days after the bone marrow transplant, Kate's white cell counts begin to rise, proof of engraftment. To celebrate, Brian insists that he is taking me out to dinner. He arranges for a private-duty nurse for Kate, makes reservations at XO Café, and even brings me a black dress from my closet.

(My Sister's Keeper: 234-235)

Treatment always gives some effects to the person who has done it. It is why unexpected thing might happen to Kate suddenly. Brian asks the family to have dinner outside in order to celebrate Kate's condition. He chooses having dinner outside because they do not go outside for a long time. However, Brian chooses to hire a private-duty nurse for Kate when they go outside for dinner. It is because Kate illness could come anytime. Therefore, the nurse could care Kate if unexpected thing happen. With the result, they can have dinner safety and comfortably.

From those evidences, the difference between Sara and Brian could be concluded. Sara adapts with some treatment regimens for Kate such as giving her growth factor shots. Besides, she also adapts with behavior change in order to Kate's happiness. In opposite, Brian adapts with the effect of treatment regimens by proposing a new way, therefore, they could enjoy their time together.

3.2.5. Communicating

Parents have to learn to communicate effectively with the professionals. It is an important thing for them because they can get a lot

of information about the child's illness. Besides, they also need to communicate with other people to support them in facing this situation.

Sara prefers to have a good relationship with professional for Kate's welfare. It is proved from the data below:

In the hallway, I approach Steph, a nurse who has just come on duty and who's known Kate for years. The truth is, I am just as surprised about Taylor's lack of information as Kate is. He knew she was coming here.

"Taylor Ambrose," I ask Steph. "Has he been in today?"

She looks at me blinks.

"Big kid, sweet. Hung up on my daughter," I joke.

"Oh, Sara ... I Steph says. "He died this morning."

(My Sister's Keeper: 320)

Sara recognizes some doctors and nurses of oncology, especially they have cared Kate years. One of them is Steph, an oncology nurse. When Kate loses contact with Taylor, one of leukemia patient she loves, Sara becomes worried. It is because Kate undergoes stem cell transplant while she is an emotional wreck. Then, Sara looks for the information about him by asking with Steph. To have a good relation with professional is very important for parent.

In addition, Sara needs to communicate with relatives and friends.

It is described in the quotation below:

I shake my head. "It just doesn't end." Donna nods, and because she completely understand, I find myself talking. And talking. And when I have spilled all my secrets, I take a deep breath and realize that I have been talking for an

hour straight. “Oh my God,” I say. “I can’t believe I wasted too much of your time.”

“It wasn’t a waste,” Donna replies. “And besides, my shift ended a half hour ago.”

(My Sister’s Keeper: 231)

Sara decides to tell Donna her secrets. She tells everything makes her being worried and frightened, especially about Kate. Then, she tells her anxious in one hours. After telling to Donna, she feels more free of worry about her daughter condition.

Besides, Sara also makes a call with her sister to tell her daughter’s condition. It is showed in the quotation below:

The angle that arrives is wearing Armani and barking into a cell phone as she enters the hospital room. “Sell it,” my sister orders. “I don’t care if you have to set up a lemonade stand in Faneuil Hall and give the shares away, Peter. I said sell.” She pushes a button and hold out her arms to me. “Hey,” Zanne soothes when I burst into tears. “Did you really think I’d listen to you told me not to come?”

“But –”

“Faxes. Phones. I can work from your home. Who else is going to watch Jesse?”

(My Sisters’ Keeper: 71)

Sara has lack of information about Suzanne for years because of a dispute. She finally decides to make a call for her. She tells about Kate’s illness and the family condition. However, she convinces her sister to do not come to the hospital. Beyond belief, Zanne comes to the hospital in order to support her and helps her in caring the children.

Father prefers to communicate with his employers. It is proved in the data below:

The dispatcher at the fire station tells me that Brian is on a medical call. He left with the rescue truck twenty minutes ago. I hesitate, and look down at Kate, who's slumped in one of the plastic seats in the hospital waiting room. A medical call.

I think there are crossroads in our lives when we make grand, sweeping decisions without even realizing it. Like scanning the newspaper headline at a red light, and therefore missing the rouge van that jumps the line of traffic and causes an accident. Entering a coffee shop on a whim and meeting the man you will marry one day, while he's digging for change at the counter. Or this one: instructing your husband to meet you, when for hours you have been convincing yourself this is nothing important at all.

"Radio him," I say. "Tell him we're at the hospital."

There is a comfort to having Brian beside me, as if we are now a pair of sentries, a double line of defense. We have been at Providence Hospital for three hours, and with every passing minute it gets more difficult to device myself into believing that Dr. Wayne made a mistake.

(My Sister's Keeper: 30-31)

On the other hand, Brian prefers to communicate with his employers. It is in order to get permission when he has to come to hospital immediately. When he gets a calling to come to the hospital, the employers would give his permission. It is because they know well the condition of his daughter. However, when an emergency thing happens in his office, Brian has to come immediately to the office.

Father and mother have role parent diverge. Mother tends to prefer communicating with the professionals in order to get more information

about her daughter. She decides to have a good relation with them.

Moreover, she also needs relatives and friends. She wants to share her feeling and tells everything to them. It is on the purpose of alleviation her emotion. On the contrary, father prefers to highlight the good communicating with employers. It is to have permission if he has to go to the hospital because of explosive situation.

In the end of this novel, Kate is still alive. She gets kidney donor from her sister, Anna. Anna dies because of a car accident. Then, her kidney is given to Kate. Before Anna is in a car accident, Kate is in the clutch. She has a kidney failure, so that she needs kidney donor. If she does not get it, she will die. However, after getting donor from her sister, she is can alive for some years later.

CHAPTER IV

CONCLUSIONS AND SUGGESTIONS

After analyzing the data, the researcher has conclusions and suggestions related to the previous chapters. In this chapter, the researcher presents the conclusion of the whole analysis and suggestions for the further research related to this study.

4.1. Conclusions

Based on the previous chapter, the researcher concludes that there are six parenting strategies used by Sara and Brian Fitzgerald in *My Sister's Keeper* novel. Those are trusting relationship, presence, emotional support, advocacy, routines and ritual, and effacing oneself. A trusting relationship is the one way to express 'being there'. Parents have to say the truth in order to get children's trust. Trusting relationship is very needed between the parents and the children. It is done when Sara is truly near with Kate when she undergoes pre-transplant regiment. Besides, Kate also believes in her mother when she will do drawing blood. Presence is the other forms of 'being there'. Parents hope to be near with a palliative child and to know first what happen to her. Sara and Brian Fitzgerald are behind the child in some situations. Those are Kate vomits many times after diagnosing as an APL, Kate's illness is back, Kate slips into a comma, and Kate's is in end-of-life. Emotional support shows that parents know their child best. They know what make their

child is afraid and how to cope with it. Sara knows what she has to do when Kate's stomach is sick and Kate has rectal bleeding. Besides, she asks the nurse to give Kate platelet when she vomits the blood.

Advocacy is a form of 'being there'. Parents always advocate for the goal of the child. Moreover, they decide to do important thing for child's health. Sara advocates Kate to undergo kidney transplant. Besides, Sara also decides to do a new therapy for Kate. Rituals and routines are continued and introduced for the illness of the child. Rituals and routines are done through the playing with Kate three-years-old, reserving isolation, celebrating Thanksgiving Day, celebrating Kate's birthday, playing football together, introducing new ritual in daily life and in having dinner outside. Effacing oneself shows that the child as a priority. Parents efface their feelings and need. It is showed Sara and Brian efface their own needs, and Sara ignores her illness and feeling.

Furthermore, Sara and Brian are different in caring a child with cancer in five aspects. Those are processing large amounts of information, sharing or negotiating caregiving, restraining children, adapting to treatment regimens, and communicating. Parents have role divergence in taking care of Kate. Therefore, they do different care for Kate in those five aspects.

4.2. Suggestions

The last section in this chapter is suggestion. Since this study is not a complete study, the researcher suggests to the next researchers who want to

conduct the research with same novel and issue to have more complete analysis to the novel. The next researcher hopefully can analyze the parenting strategies for other children, Jesse or Anna.



A Summarizing Table

No.	Parenting Strategies	Father's Strategies	Mother's Strategies
1.	Processing large amounts of information	Tend to prefer the bigger picture about the illness	Tend to prefer short-term in dealing with the information
		Take long-term view to the cancer child	
2.	Sharing or negotiating caregiving	Cannot be close with the child with cancer every time	Focus on taking care of the cancer child
3.	Restraining children	Hold the child spontaneously	Does not hold the child spontaneously
			Give hug to the cancer child
4.	Adapting to treatment regimens	Adapt with the effects of the treatment regimens	Adapt with some treatment regimens
5.	Communicating	Prefer to highlight the good communicating with the employers	Prefer to communicate with the professionals, relatives, and friends

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APPENDIXES

APPENDIX 1: DATA COLLECTION

No	Data	Category	Page
1	<p>When the pediatric nurse comes in with her tray, her syringe, her vials, and her rubber tourniquet, Kate starts to scream. I take a deep breath. “Kate, look at me.” Her cries bubble down to small hiccups. “It’s just going to be a tiny pinch.”</p> <p>“Liar,” Jesse whispers under the breath.</p> <p>Kate relaxes, just the slightest bit.</p>	A trusting relationship	See Sara: 29
2	<p>When the therapist comes to take her into the RT suite, Kate latches on to my leg. “Honey,” Brian says, “it’s gonna be fine.”</p> <p>She shakes her head and burrows closer. When I crouch down, she throws herself into my arms. “I won’t take my eyes off you,” I promise.</p> <p>The room is large, with jungle murals painted on the walls. The linear accelerators are built into the ceiling and a pit below the treatment table, which is little more than a canvas cot covered with a sheet. The radiation therapist places thick lead pieces shaped like beans onto Kate’s chest and tells her not to move. She promises that when it’s all over, Kate can have a sticker.</p> <p>I stare at Kate through the protective glass wall.</p>	A trusting relationship	See Sara: 104-105

3	<p>When Kate isn't vomiting, she's crying. I sit on the edge of the bed, holding her half on my lap. The nurses do not have time to nurse. Short-staffed, they administer antiemetics in the IV; they stay for a few moments to see how Kate responds – but inevitably they are called elsewhere to another emergency and the rest falls to us. Brian, who has to leave the room if one of our children gets a stomach virus, is a model of efficiency: wiping her forehead, holding her thin shoulders, dabbing tissues around her mouth.</p>	Presence	See Sara: 64-65
4	<p>“Hey.” Brian touches the crown of my head. He juggles Jesse in his other arm. It is nearly noon, and we are still in pajamas; we never thought to take a change of clothes. “I'm gonna take him down to the cafeteria; get some lunch. You want something?”</p> <p>I shake my head. Scooting my chair closer to Kate's bed, I smooth the covers over her legs. I take her hand, and measure it against my own.</p> <p>Her eyes slit open. For a moment she struggles, unsure of where she is.</p>	Presence	See Sara: 70
5	<p>Against all odds, Kate survives for ten days on intense transfusions and arsenic therapy. One the eleventh day of her hospitalization, she slips into a coma. I decide I will keep a</p>	Presence	See Sara: 266

	bedside vigil until she wakes up.		
6	<p>When Brian falls asleep, draped over the foot of the bed, I take Kate's scarred hand between both of mine. I trace the ovals of her nails and remember the first time I painted them, when Brian couldn't believe I'd do that to a one-year-old. Now, twelve years later, I turn over her palm and wish I knew how to read it, or better yet, how to edit that lifeline.</p> <p>I pull my chair closer to the hospital bed.</p>	Presence	See Sara: 271
7	<p>"Kate!" My mother sinks down to the floor, that stupid skirt a cloud around her. "Kate, honey, what hurts?"</p> <p>Kate hugs a pillow to her stomach, and tears keep streaming down her face. Her pale hair is stuck to her face in damp streaks; her breathing's too tight.</p>	Emotional support	See Anna: 11
8	<p>The minute we hit the ER driveway, my mother's out of the car, hurrying me to get Kate. We are quite a picture walking through the automatic doors, me with Kate bleeding in my arms, and my mother grapping the first nurse who walks by. "She needs platelets," my mother orders.</p>	Emotional support	See Jesse: 97
9	<p>It starts when Kate screams in the bathroom. I race upstairs and jimmy the lock to find my nine-years-old standing in front of a toilet splattered with blood.</p>	Emotional support	See Sara: 224

	<p>Blood runs down her legs, too, and has soaked through her underpants. This is the calling card for APL – hemorrhage in all sorts of masks and disguises. Kate’s had rectal bleeding before, but she was a toddler, she would not remember. “It’s all right,” I say calmly.</p> <p>I get a warm washcloth to clean her up, and find a sanitary napkin for her underwear.</p>		
10	<p>... “Can you still do a transplant?” she asks, as if Anna never started her lawsuit, as if it means absolutely nothing.</p> <p>“Kate’s in a pretty grave clinical state,” Dr. Chance tells her. “I told you before I don’t know if she was strong enough to survive that level of surgery; the odds are even slighter now.”</p> <p>“But if there was a donor,” she says, “would you do it?”</p>	Advocacy	See Jesse: 97
11	<p>“It’s a very new therapy,” Dr. Chance explains. “You get it intravenously, for twenty-five to sixty days. To date, we haven’t effected a cure with it. That’s not to say it might not happen in the future, but at the moment, we don’t even have five-year survival curves – that’s how new the drug is. As it is, Kate’s exhausted cord blood, allogeneic transplant, radiation, chemo, and ATRA. She’s lived ten years past what any of us would have expected.”</p> <p>I find myself nodding already.</p>	Advocacy	See Sara: 264

	<p>“Do it,” I say, and Brian looks down at his boots.</p>		
12	<p>Kate sits in her car seat, eating animal crackers. “Play,” she commands.</p> <p>In the rearview mirror, her face is luminous. Objects are closer than they appear. I watch her hold up the first cracker. “What does the tiger says?” I manage “Rrroar.” She bites off its head, then waves another cracker.</p> <p>“What does the elephant says?”</p> <p>Kate giggles, then trumpets through her nose.</p>	Routines and rituals	See Sara: 35
13	<p>Since Day Six, when Kate’s blood cell and neutrophil counts began to plummet, she has been in reserve isolation. Any germ in the world might kill her now; for this reason, the world is made to keep its distance. Visitors to her room are restricted, and those who are allowed in look like spacemen, gowned, and masked. Kate has to read picture books while wearing rubber gloves. No plants or flowers are permitted, because they carry bacteria that could kill her. Any toy given to her must be scrubbed down with antiseptic solution first. She sleeps with her teddy bear, sealed in a Ziploc bag, which rustles all night and sometimes wakes her up.</p>	Routines and rituals	See Sara: 105
14	<p>One Thanksgiving when Kate was not in the hospital, we actually pretended to be a regular</p>	Routines and rituals	See Anna: 136-137

	<p>family. We watched the parade on TV, where a giant balloon fell prey to a freak wind and wound up wrapped around a NYC traffic light. We made our own gravy. My mother brought the turkey's wishbone out to the table, and we fought over who would be granted the right to snap it. Kate and I were given the honors. Before I got a good trip, my mother leaned close and whispered into my ears, "You know what to wish for." So I shut my eyes tight and thought hard of remission for Kate, even though I had been planning to ask for a personal CD player, and got a nasty satisfaction out of the fact that I did not win the hug-of-war.</p> <p>After we ate, my father took us outside for a game of two-one-two touch football while my mother was washing the dishes.</p>		
15	<p>Downstairs, there are twenty-five second-graders, a cake in the shape of a unicorn, and a local college kid hired to make swords and bears and crowns out of balloons. Kate opens her presents – necklaces made of glittery beads, craft kits, Barbie paraphernalia. She saves the biggest box for last – the one Brian and I have gotten her. Inside a glass bowl swims a fantail goldfish.</p>	Routines and rituals	See Sara: 164
16	<p>Laughter rises like steam, swims through the windows. After three days of a torrential downpour, the kids are delighted to be</p>	Routines and rituals	See Sara: 175-176

	outside, kicking around a soccer ball with Brian. When life is normal, it is so normal.		
17	Twenty-one days after the bone marrow transplant, Kate's white cell counts begin to rise, proof of engraftment. To celebrate, Brian insists that he is taking me out to dinner. He arranges for a private-duty nurse for Kate, makes reservations at XO Café, and even brings me a black dress from my closet.	Routines and rituals	See Sara: 234-235
18	At home, we all wear masks so that Kate doesn't have to. I find myself checking her fingernails while she brushes her teeth or pours cereal, to see if the dark ridges made by the chemo have disappeared – a sure sign of the bone marrow transplant's success. Twice a day I give Kate growth factors shots in the tigh, a necessity until her neutrophil count tops one thousand. At that point, the marrow will be reseeded itself.	Routines and rituals	See Sara: 238
19	We have been shopping for a prom dress for hours. Kate has only two days to prepare for this dance, and it has become an obsession: what she will wear, how she will do her makeup, if the band is going to play anything remotely decent. Her hair, of course, is not an issue; after chemo she lost it all. She hates wigs – they feel like bugs on her scalp, she says – but she's too self-conscious to go	Routines and rituals	See Sara: 315-316

	<p>commando. Today, she was wrapped a batik scarf around her head, like a proud, pale African queen.</p>		
20	<p>“Hey.” Brian touches the crown of my head. He juggles Jesse in his other arm. It is nearly noon, and we are still in pajamas; we never thought to take a change of clothes. “I’m gonna take him down to the cafeteria; get some lunch. You want something?”</p> <p>I shake my head.</p>	Effacing oneself	See Sara: 70
21	<p>Day Zero of Kate’s pre-transplant regimen starts the morning after Anna is born. I come down from the maternity ward and meet Kate in Radiology. We are both wearing yellow isolation gowns, and this make her laugh. “Mommy,” she says, “we match.”</p>	Effacing oneself	See Sara: 104
22	<p>“I’m hungry.” He nods at the fruit in my hands. “And you’re already got a patient.”</p> <p>“For all you know that someone else’s. God knows what it’s doped up with.”</p> <p>Suddenly Dr. Chance turns the corner and approaches us. Donna, an oncology nurse, walks behind him, brandishing an IV bag filled with crimson liquid. “Drum roll,” he says.</p> <p>I put down my orange, follow them into the anteroom, and suit up so that I can come within ten feet of my daughter.</p>	Effacing oneself	See Sara: 106

23	<p>... “The thing about leukemia,” one nurse explains, “is that we haven’t even inserted a needle for the first treatment when we’re already thinking three treatments down the line. This particular illness carries a pretty poor prognosis, so we need to be thinking ahead to what happens next. What makes APL a little trickier is that it’s a chemoresistant disease.”</p> <p>“What’s that?” Brian asks.</p> <p>“Normally, with myelogenous leukemias, as long as the organs hold up, you can potentially reinduce the patient into remission every time there’s a relapse. ...”</p> <p>“Are you saying,” Brian swallows. “Are you saying she’s going to die?”</p> <p>“I’m saying there are no guarantees.”</p>	Processing large amount of information	See Sara: 61-62
24	<p>When Kate was born, I used to imagine how beautiful she would be on her wedding day. Then she was diagnosed with APL, and instead, I’d imagine her walking across a stage to get her high school diploma. When she relapsed, all this went out the window: I pictured her making it into her fifth birthday party. Nowadays, I don’t have expectations, and this way she beats them all.</p>	Processing large amount of information	See Brian: 43
25	<p>The nurse hangs the infusion bags on the IV pole and</p>	Processing large amount of information	See Sara: 64

	<p>smoothes Kate’s hair. “Will she feel it?” I ask.</p> <p>“Nope. Hey, Kate, look here.” She points to the bag of Danurobicin, covered with a dark bag to protect it from light. Spotting it are brightly colored stickers she’s helped Kate make while we were waiting. I saw one teenager with a Post-it on his: Jesus saves. Chemo scores.</p>		
26	<p>“Okay,” Brian says. He claps his hands together, as if he is gearing up for a football game. “Okay.”</p> <p>Kate pulls her head away from my skirt. Her cheeks are flushed, her expression wary.</p> <p>This is a mistake. This is someone else’s unfortunate vial of blood that the doctor has analyzed. Look at my child, at the shine of her flyaway curls and the butterfly flight of her smile – this is not the face of someone dying by degrees.</p>	Processing large amount of information	See Sara: 34
27	<p>He is talking about my little girl as if she were some kind of machine: a car with a faulty carburetor, a plane whose landing gear is stuck. Rather than face this, I turn away just in time to see one of the misbegotten leaves on the plant make its suicide plunge to the carpet. Without an explanation I get to my feet and pick up the planter. I walk out of Dr. Chance’s office, past the receptionist and the other shell-shocked parents waiting with their sick children.</p>	Processing large amount of information	See Sara: 66

	At the first trash receptacle I find, I dump the plant and all its desiccated soil.		
28	<p>When Kate isn't vomiting, she's crying. I sit on the edge of the bed, holding her half on my lap. The nurses do not have time to nurse. Short-staffed, they administer antiemetics in the IV; they stay for a few moments to see how Kate responds – but inevitably they are called elsewhere to another emergency and the rest falls to us. Brian, who has to leave the room if one of our children gets a stomach virus, is a model of efficiency: wiping her forehead, holding her thin shoulders, dabbing tissues around her mouth. "You can get through this," he murmurs to her each time she spits up, but he may only be talking to himself.</p> <p>And I, too, am surprising myself. With grim resolve I make a ballet out of rinsing the emesis basin and bringing it back.</p>	Sharing or negotiating caregiving	See Sara: 64-65
29	<p>... "We're going to the ER," I announce, although Brian is already wrapping Kate's blankets around her and lifting her out of her crib. We bustle her to the car and start the engine and then remember that we cannot leave Jesse home alone.</p> <p>"You go with her," Brian answers, reading my mind. "I'll stay here." But he doesn't take his eyes off Kate.</p>	Sharing or negotiating caregiving	See Sara: 68-69

30	<p>My father calls at eleven o'clock to ask if I want him to come get me. "Mom's going to stay at the hospital," he explains. "But if you don't want to be alone in the house, you can sleep at the station."</p>	Sharing or negotiating caregiving	See Anna: 131
31	<p>One day my sister arrives unannounced, and with Brian's permission, spirits me away to a penthouse suite at the Ritz Carlton in Boston. "We can do anything you want," she tells me.</p>	Sharing or negotiating caregiving	See Sara: 174
32	<p>Finally Brian leans down, kisses Kate's forehead. "Baby, you get a good night's sleep." As Anna and Jesse slip into the hall, he kisses me good-bye too. "Call me," he whispers.</p> <p>And then, when they are all gone, I sit down beside my daughter. Her arms are so thin I can see the bones shifting as she moves; her eyes seem older than mine.</p>	Sharing or negotiating caregiving	See Sara: 395
33	<p>My beeper goes off just as Kate starts another course of dialysis. An MVA, two cars, with PI – a motor vehicle accident with injuries. "They need me," I tell Sara. "You'll be okay?"</p>	Sharing or negotiating caregiving	See Brian: 413
34	<p>Kate relaxes, just the slightest bit. The nurse lays her down on the examination table and asks me to hold down her shoulders. I watch the needle break the white skin of her arm; I hear the sudden scream – but there isn't</p>	Restraining children	See Sara: 29

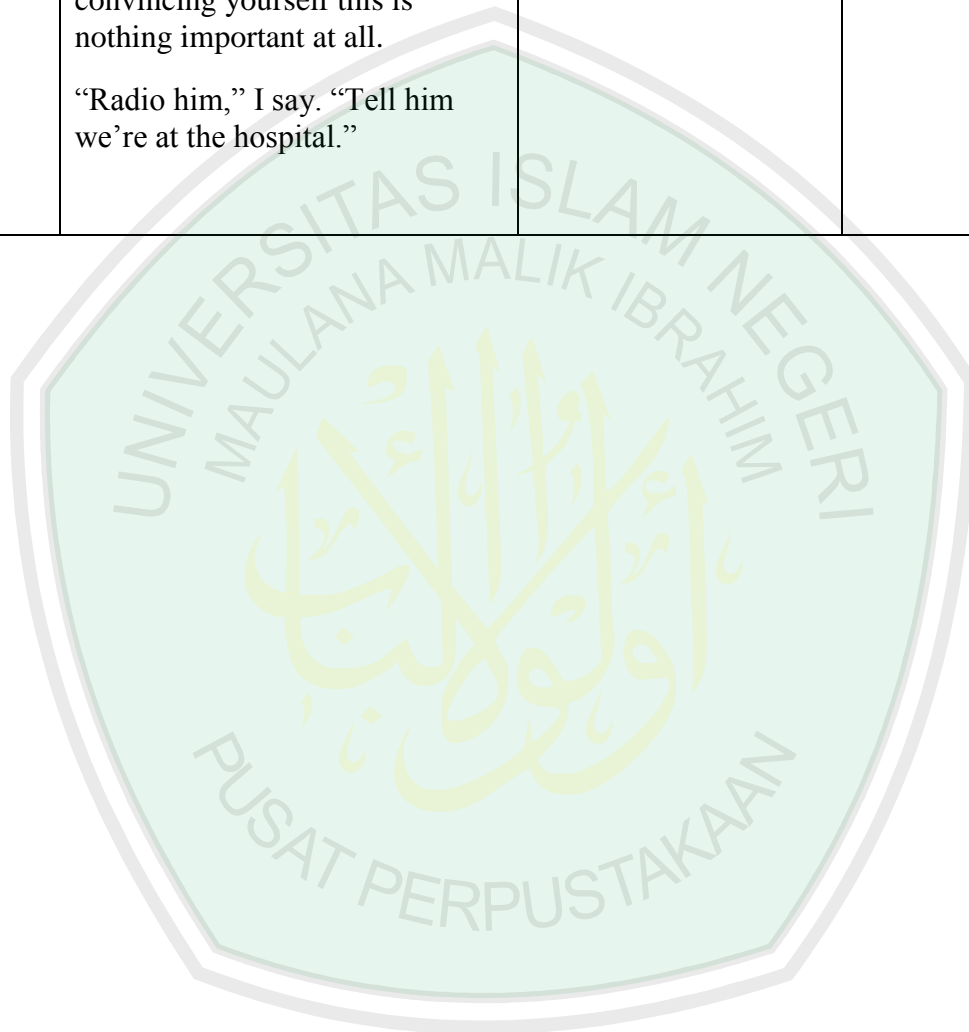
	any blood flowing.		
35	Brian brings Jesse to the hospital for his blood test: a simple finger stick. He needed to be restrained by Brian and two male residents; he screams down the hospital.	Restraining children	See Sara: 65
36	When the therapist comes to take her into the RT suite, Kate latches on to my leg. "Honey," Brian says, "it's gonna be fine." She shakes her head and burrows closer. When I crouch down, she throws herself into my arms. "I won't take my eyes off you," I promise.	Restraining children	See Sara: 104-105
37	Mom, you want to hold her on your lap?" So I crawl onto the table and settle Anna in my arms. Brian gets stationed behind us, so that he can grab Anna's shoulder and elbow and keep it immobilized. "You ready?" the doctor asks Anna, who is still smiling.	Restraining children	See Sara: 170
38	Brian and I sit outside the anteroom, waiting. While Kate sleeps, I practice giving injections to an orange. After the transplant Kate will need growth factor shots, and the core will fall to me. I prick the syringe under the thick skin of the fruit, until I feel the soft give of tissue underneath. The drug I will be giving is subcutaneous, injected just under the skin. I need to make sure the angle is right and that I am giving the proper amount of pressure. The speed	Adapting to treatment regimens	See Sara: 106

	<p>with which you push the needle down can cause more or less pain. The orange, of course, doesn't cry when I make a mistake. But the nurses still tell me that injecting Kate won't feel much different.</p>		
39	<p>In preparation for the bone marrow harvest, I have to give Anna ongoing growth factor shots, just like I once gave Kate after her initial cord blood transplant. The intent is to hyper-pack Anna's marrow, so that when it is time to withdraw the cells, there will be plenty for Kate.</p> <p>Anna has been told this, too, but all she knows is that twice a day, her mother has to give her a shot.</p> <p>We use EMLA cream, a topical anesthetic. The cream is supposed to keep her from feeling the prick of the needle, but she still yells. I wonder if it hurts as much as having your six-years-old stare you in the eye and say she hates you.</p>	Adapting to treatment regimens	See Sara: 226
40	<p>She turns to me and tries to speak, but coughs up phlegm instead. "Drown," she chokes out.</p> <p>Raising the suction tube she's clutching in her hand, I clear out her mouth and throat. "I'll do it while you rest," I promise, and that is how I come to breathe for her.</p>	Adapting to treatment regimens	See Sara: 229

41	<p>“Where do you think we’ll go out?”</p> <p>I think of Brian, who has always said that Kate can date ... when she’s forty. “Let’s take one step at a time,” I suggest. But inside, I am singing.</p>	Adapting to treatment regimens	See Sara: 309
42	<p>Twenty-one days after the bone marrow transplant, Kate’s white cell counts begin to rise, proof of engraftment. To celebrate, Brian insists that he is taking me out to dinner. He arranges for a private-duty nurse for Kate, makes reservations at XO Café, and even brings me a black dress from my closet.</p>	Adapting to treatment regimens	See Sara: 234-235
43	<p>In the hallway, I approach Steph, a nurse who has just come on duty and who’s known Kate for years. The truth is, I am just as surprised about Taylor’s lack of information as Kate is. He knew she was coming here.</p> <p>“Taylor Ambrose,” I ask Steph. “Has he been in today?”</p> <p>She looks at me blinks.</p> <p>“Big kid, sweet. Hung up on my daughter,” I joke.</p> <p>“Oh, Sara ... I Steph says. “He died this morning.”</p>	Communicating	See Sara: 320
44	<p>I shake my head. “It just doesn’t end.” Donna nods, and because she completely understand, I find myself talking. And talking. And when I have spilled all my secrets, I take a deep breath and realize that I have been talking</p>	Communicating	See Sara: 231

	<p>for an hour straight. “Oh my God,” I say. “I can’t believe I wasted too much of your time.”</p> <p>“It wasn’t a waste,” Donna replies. “And besides, my shift ended a half hour ago.”</p>		
45	<p>The angle that arrives is wearing Armani and barking into a cell phone as she enters the hospital room. “Sell it,” my sister orders. “I don’t care if you have to set up a lemonade stand in Faneuil Hall and give the shares away, Peter. I said sell.” She pushes a button and hold out her arms to me. “Hey,” Zanne soothes when I burst into tears. “Did you really think I’d listen to you told me not to come?”</p> <p>“But –”</p> <p>“Faxes. Phones. I can work from your home. Who else is going to watch Jesse?”</p>	Communicating	See Sara: 71
46	<p>The dispatcher at the fire station tells me that Brian is on a medical call. He left with the rescue truck twenty minutes ago. I hesitate, and look down at Kate, who’s slumped in one of the plastic seats in the hospital waiting room. A medical call.</p> <p>I think there are crossroads in our lives when we make grand, sweeping decisions without even realizing it. Like scanning the newspaper headline at a red light, and therefore missing the rouge van that jumps the line of traffic and causes an accident. Entering a coffee shop on a</p>	Communicating	See Sara: 30-31

	<p>whim and meeting the man you will marry one day, while he's digging for change at the counter. Or this one: instructing your husband to meet you, when for hours you have been convincing yourself this is nothing important at all.</p> <p>"Radio him," I say. "Tell him we're at the hospital."</p>		
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APPENDIX 2: CURRICULUM VITAE

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Educational Background:

1. English Letters and Language Department, Maulana Malik Ibrahim State Islamic University, Malang (2012-2016)
2. MAN Mejayan Madiun (2009-2012)
3. MTsN Termas, Baron, Nganjuk (2006-2009)
4. MI Nurussalam Jenar, Patianrowo, Nganjuk (2000-2006)
5. RA Perwanida Jenar, Patianrowo, Nganjuk (1998-2000)

Organizational Experiences:

1. OSIS (Organisasi Siswa Intra Sekolah) MAN Mejiyan in 2009/2010 and 2010/2011
2. Pramuka MAN Mejiyan in 2009/2010 and 2010/2011
3. OSIS MTsN Termas in 2006/2007 and 2007/2008
4. Pramuka MTsN Termas in 2006/2007 and 2007/2008
5. PMR (Palang Merah Remaja) MTsN Termas in 2006/2007

PKLI Experiences:

1. PM (Pengabdian Masyarakat) UIN Maulana Malik Ibrahim State Islamic University of Malang in Kalipare Malang in 2014
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APPENDIX 3: THE EVIDENCES OF CONSULTATION



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No	Date	Material	Signatures of Advisor
1.	Mei 17, 2016	Consultation of Chapter I	1.
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7.	June 13, 2016	Revision of Chapter III	7.
8.	June 16, 2016	Revision of Chapter IV	8.
9.	June 20, 2016	All Chapters, Thesis Agreement	9.

Malang, June 20, 2016

Acknowledged by
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