ABSTRACT
At least, children with acute lymphoblastic leukemia (ALL) force the children to follow long period protocols. This situation was complex due to children and parents. When they permit the treatment, it make more easy to survive but depend on parents support. This research is to explore parents caring role on children with ALL. This qualitative study held in Yogyakarta at June 2014, data collected by indepth interview with 8 parent’s from children with ALL. Data was recorded, transcribing and analized using collaizi method. During the illness, parent caring the children at home with independendent care, bringing to the hospital and giving complementary medicine. At early treatment they decide to go to traditional medicine, but at present it didn’t show more benefit than follow the ALL protocol’s. Complexity situation of treatment cause parents role strain. They face this stressor by delegating caring role of health children and economic function to the other family members.. Parent changing role during caring the children was one way to maintain family structure.

Key words: parents, action, role, leukemia

INTRODUCTION
Leukemia is the most common cancer in children. International Agency for Study on Cancer (IARC) revealed that children around the world who suffer from cancer is about 250.000 (Cutland, 2011). Cancer as a chronic disease that can cause many problems. The highly costs burden of chronic disease treatment resulting in greater losses due to lost productivity and a decrease in quality of life (Friedman, Bowden, & Jones, 2003). In long time, parents will be faced by a series of treatment protocols for children. One of the treatment protocol for Acute Lymphoblastic Leukemia (ALL) includes three stages of treatment, induction- remission phase, consolidation and maintenance should be done in at least 2.5 years (Imbach, Kuhne, & Arceci, 2004).

This condition, caring and long period of treatment may cause family unsustainability, providing threat on physic, emotional and effected family functioning (Hitchcock, Schubert, & Thomas, 1999). In family centered care perspectives, family is the main subject on caring. Family wouldn’t separated from child because they are who most closest with them, prior caregiver to the child to maintain health status (Friedman, Bowden, & Jones, 2012). As usual, parents role devided into formal and informal role (Friedman et al., 2003).

Changing role when caring children with cancer was surprisingly, although there were sharing responsibility, many problems may appear (Svavarsdottir, 2005). At the present, parents role were changing depend on many situation. In Indonesia, children health status depend on their parent as prior caregiver, including children with ALL. Futhermore, this research explore parents caring role in children with Acute Lymphoblastic Leukemia.

METHOD
This research use qualitative method. Data collected from 8 parents of children with ALL in Yogyakarta during June 2014 use indepth interview. Data was recorded and transcribed then analize use collaizi method.
**RESULT**

**Parent Plan Action During The Illness**

Table 1. Parent’s Plan Action During ALL Illness

<table>
<thead>
<tr>
<th></th>
<th>At Home</th>
<th>Rest Schedule for Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Independent Care</td>
<td>Managing nutrition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Activity Management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Providing basic health care instrument for check up</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Giving health education to health behavior, including the sibling</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilitating health education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Monitoring and providing drugs therapy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Bringing to Health Care Provider</th>
<th>Traditional medicine (massage, kyai)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td></td>
<td>Brining to the hospital from primary to advance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Following LLA protocol’s</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accompanying Children during hospital care</td>
</tr>
</tbody>
</table>

|   | Giving Complementary Medicine | Mangosten, propolis, jamu, cekok, kuyit putih, temulawak, temuireng, honey, sari kurma, jambu biji |

As shown in table 1, parent organizing their activity since their children were diagnosed with ALL. At first time they bring the children into traditional medicine, by massage, or bringing to kyai who believed as spiritual coacher. “I bring to kyai, it’s our way to find the healing”(R2)

But at present time they don’t feel better and decide to bring the children to the doctor. “Bring him to the hospital, medical instrument were good and the disease were unknown (before) “(R6)

During the LLA protocol’s, children must be on intensive monitoring from side effect, bad condition that may be worse or complication. To maintain physical condition on children, parent’s do several thing as an independent care at home, such as rest schedule that must be done by children. Sometimes they force the children to discipline them. “We force her.at time to bed, she must do it to take a rest” (R1)

Parents not only do medical administering for caring the children, during the duration of ALL, they complete this with complementary medicine, to persist health status and prevent from bad condition to the body. “the fact is after he consuming jamu, his condition never drop until now”(R8)

**Delegating Role To Other Family Members**

In early treatment, at least a half of first year parents have to take care the children in hospital. In other situation, they left another health children at home with other family members (e. c. grandfather/mother, sister or brother in law) as the caregiver for them. “She with my sister” (R5)

When father accompany the children in hospital, their responsibility to work decrease and appear, they event lost their jobs. To maintain this situation, other family members actively help them to fulfill the need. “I’m working for a while, all do by my nephews” (R1)

**DISCUSSION**

Family functioning as health care provider, family member providing primary care, decision making, primary care giver and individual support, increase wellness, illness prevention, health care, maintenance chronic condition and rehabilitation (Friedman et al., 2003). When the children diagnosed on ALL, parents do several plan action not only at hospital but also at home. The describe the independent care by managing rest schedule for children, managing nutrition involving what kind of nutrition is bad or good for the children. They force to minimize or delete food with addictive, giving a big portion on fruits and vegetables. Parents play role to managing activity of the children, when and what kind of play.

After ALL chemotherapy, children faced several condition, like nausea, vomiting (Sitaresmi et al., 2009), or sometimes in hyperthermia. To prevent the children from that condition or outside infection, basic health care instruments are needed, such as mask, thermometer, hand wash, emergency drugs and multivitamin.

Since children take care at home outside hospital care, they have to interact with the others, like sibling or another family members. In this perspectives, parents initiate to other family members to giving support by maintain positive health behavior. Giving health education to other family members is one way effective. By doing this, other family members
were cooperate with parent. But the other side, siblings whose age at average more difficult to educate especially on playing and activity with the children. Parent prefer to care the ill children and result sibling reaction (Anggraeni, 2012). Last action doing by parent at home is monitoring and providing drugs therapy. Directly monitoring of drugs more dominate by mothers than fathers.

Besides independent care at home, parent treat the children to health care provider. At early illness before the doctor, they bring them to alternative medicine/traditional medicine, kyai as spiritual coacher and massage because they had saw the symptom like rubour skin, or because parent wasn’t ready to go to hospital. Later they didn’t find the benefits, then decide to bring them to the hospital. At primary hospital, all of the children got advice to advance hospital because lack of material and medical health care competencies barrier.

At the hospital, parent follow ALL protocols start from BMP, chemotherapy and others. Not at all accompanied by parents, especially for bone marrow punction (BMP). Children show protest respon during bone marrow punction, it causes stressors face by parents. Parent participation during therapy give benefits for increase parents satisfied, bonding attachment, decrease treatment period, children recovery and pain (Watt et al., 2011). The other treatment doing by parents is complementary therapy. They use herbal medicine, for example is jamu, temulawak, temuireng and propolis, honey, dates, white turmeric, guava leaves and mangosten. Traditional medicine effected javanese cultural is jamu, temulawak, temuireng and white turmeric.

Jamu come from Javanese that means traditional medicine from plants. Composition of this are plats from family Zingiberaceae (Ruslan, Bos, Kayser, Woerdenbag, & Quax, n.d.). Temulawak, temuireng and white turmeric consist of curcumin. It induced apoptosis T helper 1 cell through JNK (Jun-amino terminal kinase) and ERK (extracellular regulated kinase) and recommended for acute monosit leukemia (Yang et al., 2012).

Honey effective on healing oral mucocitis after cemotherapy than olive oil-propolis and propolis (Abdulrhm, Elbarbary, Ahmed, & Ebrahim, 2012). Active substance in honey can inhibit tumor cell growth or cancer by regulating cell cycle, mitochondrial pathway activation, induction of mitochondrial outside the permeable membranes, induction of apoptosis, oxidative stress modulation, amelioration of inflammation, modulation of insulin signaling and inhibition of angiogenesis (Erejuwa, Sulaiman, & Wahab, 2014).

In caring children with cancer, parent faced change role (Clarke, Mccarthy, Downie, Ashley, & Anderson, 2009), they delegates their role to another family member. Caregiver role was done by people who have family relationship. In women with ca mammiae, caring healthy children doing by other family members (Coyne, Wollin, & Creedy, 2012). This condition assumed that parents want to persist family structure on crisis situation.

CONCLUSION
During the illness, parent changing role by delegates their role in caring health children and fulfill the need to other family members. Although on this research have early established that parents do plan action after the children was diagnosed ALL, more follow up were needed to other research to explore home care needed for children with ALL during or following the treatment.

ACKNOWLEDGEMENTS
Greatfully thanksfull to RS Dr.Sardjito Yogyakarta, All of Participant who contributed on this research.

REFERENCES


