Introduction
Technological advances in the health sector in the last few decades have had an impact on increasing the number of children living with special needs. In 2000, the number of children of the nation who had special needs was 15.6% (Ball & Binder, 2010). Children who have special needs include children with chronic diseases/conditions, congenital disabilities, developmental delays and disabilities, disabilities, etc. (Wong & Wilson, 2001).

The National Health Interview Survey Disability Supplement for Children, 1994 states that the prevalence of chronic diseases in children aged 0-17 years according to Stein and Silver is around 10.3 million (14.8%) (Rusmil, 2013). Globe (2004) states that there are 10 million children under 18 years in the United States are in chronic conditions (Ball & Binder, 2010).

Chronic conditions in many cases become long-term life disorders. This disorder depends on the severity of the condition, the stage of growth and development when the condition is experienced and the response of the child and family (Ball & Binder, 2010). Children with chronic disease conditions will experience various changes in almost all aspects. This, if without proper treatment, will lead to a decrease in the quality of life of the child which in the end the child will not be able to survive longer and even the child will not reach adolescence.

The change from a normal health condition to an experience that is deeply felt by the child. This requires adaptation for both the child and the family. Children must adapt to the environment. The presence and support of families in the care of children with chronic conditions and special needs is urgently needed.
Families are expected to have sufficient knowledge about the care needs of sick children. Lack of knowledge about child care can cause families to experience significant stress or crisis. The inability of this family will have an impact on child care. Therefore, the nurse's role is needed to assess the family's knowledge of the child's and family's strengths, reactions to stress due to chronic conditions and coping mechanisms. Through this role, it will be able to increase the understanding of families about the care needs of sick children and increase the role of families in family centered care for children with chronic conditions.

Nurses can work with families, especially parents, in providing family knowledge in health care for children with chronic diseases. Nurses need to convey that children living with chronic diseases or disabilities generally experience functional and social limitations and thus require more specialized health care than children in general (Newacheck, 1998 in Wong & Wilson, 2001; Ball & Binder, 2010). Thus, nurses can support family coping and improve optimum family function throughout the life of children with chronic conditions.

It is important for nurses to teach parents that in the care of children with chronic diseases, children need to be treated like normal children. Efforts to normalize children can be done by adjusting the child's daily routine to the family schedule. The family environment can be encouraged to involve children in age-appropriate activities. The application of this normalization principle can ultimately minimize the disease of children, children and families can live as normal as possible, especially during treatment at home. This is the reason why researchers feel the need to analyze the influence of parental knowledge about child care on efforts to normalize children with chronic conditions so that in the end it will improve the quality of life of children.

Method
This research is an analytic observational with the data analysis used in this study in the form of descriptive statistics, namely the cross sectional method using the Chi Square test which aims to determine the percentage of parents' knowledge about the treatment of Thalassemia children to efforts to normalize children with Thalassemia.

The research variable described in the conceptual framework in this study is the knowledge of parents about treating children with thalassemia. Selected subjects / desired samples in this study are all parents who have children with Thalassemia. The sample was selected by determining the sample size using stratified random sampling. The results of the calculation of the Slovin formula obtained the number of samples in this study were 31 respondents.

Results
The results showed that the characteristics of the respondents consisted of age diagnosed with thalassemia, child's gender, history of transfusion, Hb levels, age of parents, parental education, parental knowledge as shown in table 1. The age of children when diagnosed with thalassemia was 1-5 years old that is as much as 50 percent. The sex of most children with thalassemia in the female sex as much as 62.5 percent. While the current age of most children aged above 5 years to the age of 10 years as much as 46.9 percent with an average length of time children have suffered from thalassemia for 1-5 years as much as 34.4 percent. The Hb level of each child who was treated with thalassemia was at an Hb level between 5-7 g% as much as 68.8 percent.

The description of the distribution of parental respondents shows that from the number of respondents, the most age of parents is above 41 years of age with the highest level of knowledge of parents is junior high school. The level of knowledge of parents about thalassemia disease and its treatment is mostly at the moderate level of knowledge as much as 65.6 percent. Parents who have thalassemia children on average make efforts to normalize their children as much as 65.5 percent.

The results of the analysis of the relationship between parental age and efforts to normalize thalassemia children obtained the following data: from 4 respondents aged 20 - 30 years, there were 50% who applied normalization efforts. Of the 10 respondents aged 31-40 years as much as 60% implement normalization
Efforts to Normalize Parents with Thalassemia Children, In general, this study wants to identify a description of the normalization efforts made by parents in thalassemia children. Normalization efforts that are seen are parents implementing normalization efforts or not implementing them. The results showed that of the 32 respondents who conducted the study based on the inclusion and exclusion criteria, there were 65.5% of parents who applied normalization efforts.

Thalassemia experienced by children as a chronic disease can be a major health problem not only for children as patients but also for families and the health system in general. Thalassemia can affect children's quality of life and cause disturbances in all dimensions of life. Research conducted by Koutelekos and Haliasos (2013) found depression in children, adolescents and adults who suffer from thalassemia. According to Bulan (2009), the quality of thalassemic children is also influenced by economic status, mother's education, ferritin quality, father's education, Hb level, type of iron chelation, spleen size.

The management of thalassemia as a chronic disease is to create a normal environment for children. One of these efforts can be done by nurses through normalization efforts. Normalization is a dynamic process and occurs from time to time in which there is a continuous interaction between what is considered normal identified by the individual and what normal characteristics can be achieved or maintained, thus shaping the perceptions of others (O'Neal, 2007).

Through normalization efforts made by parents can improve the quality of life of thalassemic children. Parents' awareness about the importance of taking care of children with thalassemia, including normalization efforts needs to be increased. Goyal, Hpapani and Gagiya (2107) found that parents' awareness of the disease was inadequate. For this reason, it is necessary to increase parental awareness about child care, one of which is through normalization efforts so that it can improve the quality of life of thalassemia children.

In an effort to normalize families in caring for children with chronic diseases, families must be able to adapt in living daily life, including in accommodating the physical and psychological needs of children (Hockenberry & Wilson, 2009, O'Neal, 2007). Children who suffer from thalassemia can experience various changes, both physical and psychological.

Research conducted by Halimah, Allenidekania and Waluyanti (2016) regarding the risk of thalassemia adolescents to behavior change states that adolescent boys are at risk for anxiety, social problems and decreased attention. Other factors such as multiple transfusions for more than 5 years are at risk for...
anxiety, low parental involvement with their children is at risk for social problems, while middle and low parental education each increases the risk of decreased adolescent attention. In this case the nurse is responsible for providing appropriate nursing interventions for behavioral changes that occur because the quality of life as an adult is influenced by the quality of life as a teenager. Similar research on psychological changes that can be experienced by Thalassemia children was also carried out by Yanitawati, Mardiyah, and Widianti(2017) who found that there was a relationship between sick behavior in psychosocial aspects and the quality of life of thalassemic adolescents.

The Relationship of Respondents Characteristics Factors to Normalization Efforts for Thalassemia Children

The conceptual framework of this research explains the characteristics of respondents who are considered to be able to influence efforts to normalize thalassemia children, namely the age of the parents, the level of knowledge of the parents and the level of parental education. Each of these characteristics has been analyzed by univariate and bivariate. The results of the analysis related to the characteristics of respondents and other variables can be described as follows:

a. The Relationship between Parents' Age and Efforts to Normalize Thalassemia Children

The age of parents (mother and father) in this study is thought to be one of the factors that can influence efforts to normalize thalassemia children. The results of this study were obtained from 32 respondents, most of the parents were aged above 41 years, namely 56.3 percent. Analysis of the relationship between parental age and normalization efforts concluded that the age of the majority of respondents who applied normalization efforts was as much as 72%. The results of the chi square analysis of the age factor of parents did not have a significant relationship with efforts to normalize thalassemia children ($p = 0.631$).

b. The Relationship between Parents' Education Level and Efforts to Normalize Thalassemia Children Anak

The results of the univariate analysis show that the highest level of parental education is junior high school education as much as 56.3%. Analysis of the relationship between parents' education level and efforts to normalize thalassemia children from 18 respondents with junior high school education level as much as 78% implement normalization efforts. The results of statistical tests obtained $p$ value of 0.020 so that it can be concluded that there is a relationship between parents' education level and normalization efforts.

The results of this study show that the majority of respondents are with junior high school education level. This is in accordance with research conducted by Bulan (2009) that factors related to the quality of life of children with Beta Major Thalassemia are one of them determined by the level of education of their parents. The research of Halimah, Allenidekania and Waluyanti (2016) also found that middle and low parental education each increased the risk of decreased attention in thalassemic adolescents. With a sufficient level of education, parents are expected to be able to take good care of their thalassemia children, including normalization efforts. Normalization efforts in this study are urgently needed for thalassemia children because from the results of univariate analysis of children's characteristics, most children are of school age (above 5 years) with the highest level of education being in elementary and junior high schools. At this time the child is still very high desire for self-actualization. With thalassemia experienced and having to undergo frequent hospitalization, especially having to undergo routine transfusions, the child will be disturbed in his self-actualization and can affect the quality of life of the child in the end.

The results of this study showed that the average respondent had experienced thalassemia for more than 5 years. The research of Halimah, Allenidekania and Waluyanti (2016) found that multi-transfusion of more than 5 years in thalassemic adolescents was at risk of experiencing anxiety. The average Hb level of the children in this study was below 7 grams percent. This also affects the quality of life of thalassemic children. This is in accordance with the research of Mariani, Rustina, and Nasution (2014) and the research of Bulan (2009) that one of the factors that determine the quality of life of children with Beta Major Thalassemia is the pre-transfusion Hb level. For this reason, it is clear that the education level of parents is very decisive in the treatment of thalassemia children, where parents must
understand how things can affect the quality of life of thalassemic children so that they are able to strive so that these factors can be considered in parents who have thalasemia children.

c. The Relationship of Parental Knowledge to Efforts to Normalize Thalassemia Children
The results of the univariate analysis showed that the highest knowledge of parents about thalassemia child care was at the moderate level of knowledge as much as 65.6 percent. The results of the analysis of the relationship between parental knowledge about thalassemia disease and normalization efforts can be concluded that there is a significant relationship between the level of parental knowledge on normalization efforts ($p = 0.002$).

A good level of parental knowledge in caring for thalassemia children is very much needed. As parents who have children with thalassemia disease, parents need to increase their role in normalization efforts. The role of parents in normalizing children with chronic diseases including thalassemia, among others: parents must carry out treatment regimens, parents as advocates for children's health care, both at home and at school, parents must be able to allocate time for work and other family members. In normalizing children suffering from thalassemia, parents can act as advocates for child health care. To carry out this role, a sufficient level of knowledge is needed so that parents can implement efforts to normalize their children. As child care advocates, parents need to always make time to accompany their children. Research by Halimah, Allenidekania and Waluyanti (2016) found that low parental involvement in their children is at risk for social problems.

Family support for children with thalassemia is very much needed. This is in accordance with the research of Iswantoro, Setiwati, and Khoriyah (2014) that thalassemic children need four (4) support from the family, namely wanting to be considered normal or not different from their peers, instrumental support (wanting to be appreciated, loved, and listened to), increased motivation/ strengthening the illness experienced, and increasing the family's understanding of the disease and its treatment.

The need for family support for thalasemia sufferers is also found in Pratiwi's research (2018) which states that the social support played by the mother is emotional, instrumental support, providing information, assessing and accompanying recreation while the father's role is to provide instrumental support in the form of material. One of the forms of parental support is influenced by the knowledge factor.

With a fairly good level of knowledge in treating thalassemia, parents have a lot of time and experience in caring for children. In addition, the length of time the child suffers from thalassemia can also affect the knowledge and attitudes of mothers in caring for thalassemia children. This is in accordance with Indriati's research (2011) which found mothers' experiences in caring for thalassemia children, including: not accepting the reality, trying to treat children, being a caregiver for children, challenges faced in caring for children, success as a caregiver and support received by mothers.

A good level of knowledge will have an impact on good behavior in providing health care to children. Adequate knowledge of parents about the disease is very important in increasing parental awareness as well as possible in the treatment and management of children's health that can be used in caring for and enhancing the quality of life of children. The results of research by Mariani, Rustina, and Nasution (2014) found that the average quality of life of thalassemic children was 58.6 percent. The results of research by Yanitawati, Mardiyah, and Widianti (2017) also found that the quality of life of thalassemic adolescents was low (54 percent). This result is below the value of quality of life in the normal population of $81.38+15.9$ (Month, 2009).

By increasing the level of knowledge, it is hoped that parents can correct wrong behavior in caring for children (Hakim, et.al. 2013). Nurses need to provide health education to increase parents' knowledge about efforts to normalize children which will ultimately be able to improve the quality of life of children.
with thalassemia. The research of Supartini, Sulastri and Sianturi (2013) stated that the quality of life of thalassemic children is most influenced by the attitude of the family in caring for thalassemia children. For this reason, it is necessary to provide health education to families that will affect the attitude of the family to be more positive in caring for children which will have an impact on the quality of life of thalassemic children.

Conclusion
The results of the study from 32 research respondents found that the most parents were aged more than 41 years, with the highest level of parental education being junior high school and the highest level of knowledge of parents being at a moderate level of knowledge. The results of the study found that there was no relationship between parental age and efforts to normalize thalassemia children (P value), there was a relationship between parents' education level and efforts to normalize thalassemia children (P value 0.020), and there was a relationship between the level of knowledge of parents and efforts to normalize children. thalassemia ((P value 0.002). Thus the level of knowledge has the most influence on efforts to normalize children with thalassemia. Pediatric nurses need to teach families about the importance of normalization efforts in thalassemia children which in turn can improve the quality of life of children.

References

