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Original Article

Exploring the Perceptions on Marriage and Reproductive Health Among Thalassemia Patients in Banyumas Regency

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ABSTRACT

Background: The complications of thalassemia arise due to iron overload in the bodily organs. Iron overload in the endocrine glands causes hypogonadism, which then affects the growth of reproductive organs. As a result, reproduction in thalassemia patients is not a normal procedure. Thalassemia patients considering marriage and having a family go through so many psychological problems in life, which are influenced by factors such as their socioeconomic status, adherence to treatment and complications. These factors play a role in shaping the perceptions towards marriage and reproduction of thalassemia patients. This study was aimed at exploring the perceptions surrounding marriage and reproduction. **Method**: This research was a descriptive study design conducted in Purwokerto, Central Java. Data was collected for 37 participants through interviews and questionnaires, for variables on sociodemographic, attitude to treatment, and perceptions surrounding marriage and reproduction. Data was analyzed using Microsoft excel and Minitab software version 22. **Results**: The results demonstrated that the average age of the participants was 26.41 with a standard deviation of 5.93. The youngest participant was 16 years and the oldest was 39 years old. 84% of the participants were female and 16% were male. 75% of the participants had an education level of high school or lower, 81% had economic support, and 56% had jobs with income. Most participants never abandoned blood transfusion therapy, iron chelation, and other necessary treatments. Many reported of experiencing negative impacts in their lives, despite the absence of complications. Married participants still report of experiencing infertility, while some have children. Many participants agree for prenatal diagnosis of thalassemia foetus but disagree on abortion of thalassemia foetus. Participants interviewed about their perception regarding male and female contraceptive methods, had little knowledge regarding the subject.

Keywords: *Latent TB, Risk Factor, Developing Country*

INTRODUCTION

The thalassemias are caused by the defective or absent production of one of the globin chains in the haemoglobin tetramer. According to the type of globin chains involved in the mutation, the thalassemias are distinguished from each other either as alpha, beta, or delta thalassemia.[1] Recent surveys suggest that between 300,000 and 400,000 babies are born

with a serious hemoglobin disorder each year and that up to 90% of these births occur in low- or middle-income countries (LMICs), the most common disorder being thalassemia.[2] The prevalence of thalassemia is increasing every year at a faster rate, having a widespread distribution throughout the world. Formerly the distribution of thalassemia had been mainly limited to the areas from the Mediterranean basin through the Middle East and Indian subcontinent up to 10 Southeast Asia, the so-called "thalassemia belt.[3]

The improvement of beta thalassemia treatment has led to an increased life expectancy of the patients.[4] This implies the emergence of comorbidities as a result of iron overload in the visceral organs. Iron 17 deposition occurs mainly in the heart, liver, and endocrine glands, causing tissue damage and ultimately organ dysfunction and failure.[4] Prolonged exposure to iron toxicity is involved in the development of endocrinopathy, osteoporosis, cirrhosis, renal failure, and malignant transformation. It is important to routinely monitor iron accumulation-related complications, including liver and cardiac damage in youth and adult transfusion-dependent thalassemic patients.[4]

The endocrine glands produce hormones that regulate various body functions and are extremely sensitive to iron overload. A study on the effects of iron overload on the function of endocrine glands revealed that excess iron in the endocrine tissues causes hypogonadism in both males and females.[5] Hypogonadism is a condition in which there is a diminished function in the ovaries and testes, which ultimately has a proportional effect on the production of reproductive hormones. As a result, reproduction in thalassemia patients is not a normal procedure, since it requires some amount of therapy to render the procedure to normalcy.

Complications as such have had a huge impact on the Quality of Life of thalassemia patients and their perceptions about themselves.[5] A study speculated that endocrinopathies have an impact on the daily lives of thalassemia patients.[6] While there were gaps in the literature addressing complications related to endocrinopathy, it was advisable for early recognition and treatment, as well as choosing the most appropriate therapy, according to the patient's needs (fertility, pubertal development, psychological concerns, comorbidities). [6]

The reproductive health issues of thalassemia patients are complex. The chronic nature of the condition, the complexity of its treatment, and the well documented complication of hypogonadism which leads to growth failure, delayed or absent sexual development, infertility, and osteoporosis, puts persons with this disorder at risk of reproductive disorders and possible associated psychosocial problems.[7] Although thousands of people worldwide who have thalassemia, have an increased risk for reproductive health problems and would benefit from information on good reproductive and sexual health for their overall wellbeing, the literature on these issues is scarce. Most published studies have investigated these patients' hypothalamic–pituitary–gonadal axis from an endocrine viewpoint alone.[7]

Currently, there is insufficient literature on the social barriers of marriage and reproduction in thalassemia patients. One tool used for capturing the difficulties faced by thalassemia patients is by using a patient-reported outcome measure, in particular assessing (QoL). QoL has been defined by the World Health Organization as the "net consequence of life characteristics on a person's perception of their position in life, in the context of the culture and value systems in which they live, in relation to their goals, expectations, standards, and concerns".[8] Generic QoL measures have been developed over time and this instrument measures four different aspects of the lives of thalassemia patients. The social domains of life are one of the parameters measured using the generic instrument.[9] However, this instrument does not capture the marriage and reproduction facet in depth thus, touching the tip of the iceberg in that subject. To delve deeper into this subject, two studies conducted in Greece and Iran explored the wishes

of thalassemia patients regarding marriage and reproduction. Both studies concluded that to have a deep understanding of the ethics and the social impairments regarding marriage and reproduction experienced by thalassemia patients requires more studies on the subject.[10,7] The research gap identified in both studies include how perceptions surrounding marriage and reproduction of thalassemia patients affect their social lives. This research aimed to address this existing gap and thus, identified the perceptions on marriage and reproduction of thalassemia patients

METHODS

This was a descriptive study design in which thalassemia patients from the Banyumas Thalassemia Foundation were recruited, interviewed, and asked to fill a questionnaire. The questionnaire was adapted from a previous study.[10] From approximately 100 patients who where within the reproductive age range (15 to 49), 37 participants were recruited based on the criteria. Results were recorded in excel and analysed using Minitab Software version 19

Results

1. Participants Age and Gender

From the 37 participants, 84% (n = 31) were female and 16% (n = 6) were male. The youngest participant was 16 and the oldest participant was 39. The highest frequency of ages was 22 and 24 followed by 26- and 32-year-olds. The mean age for male participants was 28.7 years old with a standard deviation of 4.3. The mean age for female participants was 25.9 years with a standard deviation of 6.1. The mean age of all participants was 26.41, with a standard deviation of 5.93.

Perspectives on Marriage and Reproduction of Participants

Regarding prevention of thalassemia at birth, 92% (n = 34) of the participants thought it necessary to prevent thalassemia at birth, while one participant thought it unnecessary to prevent thalassemia at birth. Two participants had their own thoughts on this. One participant shared that "*Taking preventive measures really need to be done. Even though we tried to prevent having a thalassemia child, if Allah allows it to happen, who are we to control it?*". Meanwhile, the other participant reported not being clear about the preventive methods. Questions on the prenatal diagnosis of thalassemia foetus reported 65% (n = 24) of the participants responded yes while 24% (n = 9) responded No. The other 4 participants chose other options. Two of the participants shared similar sentiments to that of one participant who wrote, *"Prenatal diagnosis is a difficult choice to make"*. Meanwhile the fourth participant reported not being familiar with prenatal diagnosis. While exploring the ethics surrounding abortion, 16% (n = 6) thought it ethical for abortion of foetus, while the majority 70% (n = 26) thought it unethical to perform abortion on a thalassemia foetus. The remaining five participants had other responses in which three of them reported similar views, implying that it was sad to take a life. The other two respondents thought it sinful to take an innocent life. Moreover, 14% (n = 5) ethically approved of tuba ligation while 70% (n = 26) did not approve of it. The remaining nine participants reported that they did not know what tuba ligation was. Questions regarding vasoligation reported 19% (n = 7) who approved to perform vasoligation on thalassemia husband, and 51% (n = 19) who did not approve. The remaining 11 participants reported that they did not know what vasoligation was and were never taught on the subject before.

Table 3. Perceptions on Marriage and Reproduction

Importance of marriage	**n**	**Avg Age (Yrs)**	**Gender**	
			Male	**Female**
Very much important	31	26.7	6	25
Not so important	6	24.8	Nil	6
Not important at all	0	Nil	Nil	Nil
Fallen in love and thought of marrying that person	**n**	**Avg Age (Yrs)**	**Male**	**Female**
Yes	35	25.9	6	29

No	2	19	Nil	2
Have you ever thought of marrying a thalassemia sufferer?	**n**	**Avg Age (Yrs)**	**Male**	**Female**
Yes	1	16	Nil	F
No	36	25.8	6	29
Importance of having children	**n**	**Avg Age (Yrs)**	**Male**	**Female**
Very much important	30	24.9	6	24
Not so important	6	28.8	Nil	6
Not important at all	1	27	Nil	1
Prevention of thalassemia at birth is necessary	**n**	**Avg Age (Yrs)**	**Male**	**Female**
Yes	34	25.8	5	29
No	1	23	Nil	1
Other opinion	2	22.5	1	1
Prenatal Diagnosis of thalassemia foetus	**n**	**Avg Age (Yrs)**	**Male**	**Female**
Yes	24	25.8	3	21
No	9	24.6	2	7
Other opinion	4	26	1	3
Abortion of thalassemia foetus	**n**	Avg Age (Yrs)	Male	Female
Yes	6	25.5	1	5
No	26	25.4	4	22
Other opinion	5	26.6	Nil	5
Female Contraceptive	**n**	Avg Age (Yrs)	Male	Female
Yes	5	26.8	Nil	5
No	26	25.6	5	21
Other opinion	6	26	1	5
Male Contraceptive	**n**	Avg Age (Yrs)	Male	Female
Yes	7	25.1	1	6
No	19	24.7	3	16
Other opinion	11	27.4	2	9

DISCUSSION

1.Treatment Characteristics, Complications and Impacts

From the results observed, majority of the participants received blood transfusions every 3 weeks and 4 weeks, while only a few received blood transfusion every 2 weeks and other periods. One reason for this could be the disease classification in which each participant fell under. For example, Thalassemia major patients received blood transfusions regularly every 2 weeks and 3 weeks, whereas thalassemia intermedia patients may receive blood transfusion every 4 weeks, and the thalassemia minor patients may receive blood transfusion any other periods.[14] Another reason could be because of the availability of safe and adequate blood for transfusion. In the latest Webinar presentation on the updates of thalassemia in Indonesia 2024, thalassemia specialists highlighted the challenges faced in Indonesia in which unavailability of blood transfusion was a major problem.[15] Apparently, this is a problem that is common in interior parts of Indonesia, as opposed to the big cities.

Moreover, the webinar highlighted that emergency drugs for heart complications, is unavailable in Indonesia even though these drugs are available in neighbouring countries such as Malaysia, Thailand, and Singapore. The drugs currently available, as highlighted were deferoxamine, and another local drug manufactured in Indonesia.[15] This information coincides with the results in this study, in which, majority of the participants have never abandoned iron chelation therapy and necessary treatments. These findings could also be attributed to the classification of the diseases, as discussed previously. To add on, this health seeking behaviour observed can also be attributed to the socioeconomic status, family history of the disease, and the distance from their home to the Banyumas thalassemia centre.[16] For example, a patient who has more financial support is more likely to afford iron chelation therapy and necessary treatment compared to the person who has no financial support. A similar result was observed in India in

which the health seeking behaviour of thalassemia patients were significantly associated with their caregiver's knowledge regarding the disease, parents' educational level, and socio-economic status.[17]

Iron chelators are quite expensive and with the socioeconomic status of the average Indonesian, one cannot afford iron chelators.[18] The financial burden has been addressed in Indonesia through the introduction of the National Health Insurance (NHI) scheme. This scheme embodies all existing health insurance under one body known as the Penyelenggara Jaminan Social (BPJS). The BPJS covers iron chelation and necessary treatments for thalassemia patients.[19] Blood transfusion, on the other hand, is free in the Banyumas Thalassemia Clinic. However, as revealed in the latest webinar, the funds provided through by the BPJS are not enough, especially for adult patients. Unfortunately, in each city, the funds are different in amount; the smaller cities or inner cities get much less than the larger cities.[15] Furthermore, thalassemia is one of the top five diseases that drains BPJS money.

2. Marriage and Reproduction Perspectives of Participants

The results regarding this aspect demonstrated that a huge proportion of the participants deemed marriage to be very important and a huge proportion have also fallen in love and have thought of marrying that person. This positive mindset can be attributed to the psychosocial support provided in the Banyumas Thalassemia Clinic, and a smooth transition from children's clinic to adult's clinic.[19] Psychosocial supports for thalassemia patients are successfully orchestrated with the collaboration of educators, parents and family members, social workers as well as support groups. The transition from children's clinic to adult's clinic has also been in a manner in which the sense of their "second home", would be preserved, as clinics were referred to as their second homes. This has allowed them to stay under the care of the same nurse who is a familiar face to them. This kind of clinic is not common anywhere and has also had more positive impacts towards their psychosocial outcomes.[19]

In contrast to these findings, a study in Malaysia reported that thalassemia patients always had a lower self-esteem and most of them would never disclose their thoughts regarding marriage, to their parents or care givers. Moreover, these group of participants had a negative outlook towards life.[25,26]

Many of the participants deemed it very important to have children and many had no thoughts of marrying a thalassemia sufferer. This reflects a good understanding of the disorder, among the participants and can be attributed to the positive health seeking behaviour displayed as well as the psychosocial support they receive.[19] Perceptions regarding marriage and reproduction in thalassemia patients has not fully been explored, apart from the one in Iran.[10] The study in Iran also demonstrated similar findings in which thalassemia patients with no complications, who were regularly transfused and never neglected iron chelation and other necessary therapy, were likely to deem having children as very important. Furthermore, this study also revealed that these patients would not choose a thalassemia sufferer as a partner.

3. Perceptions and Ethics on Prevention, Prenatal Diagnosis, and birth control

This study reported that the vast majority of the participants would opt to prevent thalassemia at birth and approve for prenatal diagnosis of thalassemia, although some thought it was a difficult choice to make. On the other hand, the majority of the participants did not approve for abortion, tuba ligation, and vasoligation. While some participants shared that they did not understand the process of tuba ligation and vasoligation, others that understood reported that it was a difficult choice to make. Similar studies in Iran have been conducted in which thalassemia couples preferred to choose abortion of affected foetuses rather than giving up their marriage, and some people with thalassemia major choose a person with thalassemia major as a marriage partner, though

they must give up having their own.[10] The ethics surrounding abortion is subjected to cultural practises and laws governing a society, and is influenced by religion. Abortion is legal under certain circumstances in both Iran and Indonesia, which are predominantly Muslim societies.

In Indonesia, abortion is legal if it threatens the life of the mother. In this context, thalassemia cases opting for abortion are cases that do not threaten the life of a mother and is deemed as illegal. This may change in due time, with more emphasis placed on controlling the prevalence of thalassemia through screening. To add on, the difference in views of abortion may be influenced by the difference in socioeconomic status and other factors, given that the study conducted in Iran had participants who were in the middle class and up.[10]

In conclusion, the socioeconomic status, treatment, and impacts of complications, contribute towards the perceptions on marriage and reproductive health of thalassemia patients. Thalassemia patients willing to start a family go through so many challenges and need collective support from the society and caregivers, for them to live a normal life. Thalassemia patients should also understand reproductive health through counselling. More studies are needed to fully explore the perceptions on marriage and reproductive laaah health of thalassemia patients.

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