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Awareness about Thalassemia and Its Management Among the Caregivers of the Thalassemia Patients of Punjab and Chandigarh, India

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***Abstract*---**Background: β-thalassemia is an autosomal recessive condition that causes a reduction in the production of haemoglobin. Despite their short lifespans, thalassemia patients must rely on routine blood transfusions throughout their lives. They suffer from a variety of health issues, the majority of which are caused by iron overload complications. It places a significant financial and psychological strain on both patients and their caregivers, and their perceived knowledge of the disease play a significant role in controlling and enhancing their health-related quality of life. Objective: To determine if caregivers of transfusion-dependent thalassemia patients are aware of thalassemia and how to manage it. Methods: The study examined the caregivers of 105 North Indian thalassemia patients who got blood transfusions on a regular basis in hospitals in Patiala, Punjab, and Chandigarh. With prior informed consent, caregivers were interviewed to evaluate their knowledge of thalassemia and its management with their socio-demographic characteristics. The knowledge of each caregiver was rated using a scoring system and was correlated to the caregiver's SES and education. The data was analysed using the SPSS version 20. Results: The majority of caregivers had sufficient knowledge about thalassemia and their comorbidities, premarital screening, treatment modalities,

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iron overload, and chelation therapy. However, less than half of the caregivers had knowledge of antenatal screening, prenatal diagnosis, the impact of consanguinity, and iron overload monitoring. With a minimum score of 0 and a maximum score of 21, the mean knowledge score of caregivers regarding thalassemia disease was computed as 13.61 ± 0.31. We reported a positive and substantial ($p \leq 0.05$) connection between disease knowledge and caregiver education and SES level. Conclusion: The gaps in caregivers' knowledge of thalassemic children's disease and management should be filled by scheduling regular counselling sessions and easy-to-understand awareness-raising efforts so that their actions could become better in understanding and managing patients in various disease conditions.

***Keywords*---**caregivers, thalassemia treatment, premarital screening, ferritin monitoring, iron overload.

Introduction

Thalassemia is an autosomal recessive single gene condition characterised by abnormal haemoglobin synthesis and excessive red blood cell breakdown. Each year world-wide, more than 40,000 babies are born with β-thalassemia, with roughly 25,500 of them having transfusion-dependent thalassemia also known as β-thalassemia (WHO, 2008). Thalassemia is the most prevalent, non-communicable disorder in children, with an estimated 10,000-12,000 children being affected each year with it (Dhanya et al, 2019). The Mediterranean region, the Middle East, and Southeast Asia have the highest prevalence of β-thalassemia, while Northern Europe and North America have the lowest (Colah, Gorakshakar, & Nadkarni, 2010). There are around 30-40 million carriers of thalassemia in India, with nearly 12000 infants born with thalassemia major disease each year (WHO, 2008; Mohanty et al, 2013), which equals to 10% of all thalassemic newborns born each year worldwide (Varawalla et al, 1991).

Thalassemia treatment is complicated, lifelong, and inconvenient, requiring frequent hospitalizations and blood transfusions, which can have a negative impact on a child's physical and mental health, and patients with thalassemia major still have just one option for a cure: allogeneic stem cell transplant. Individuals with low risk factors have a greater likelihood of a successful transplant, while high-risk patients have a more difficult time (Olivier, 1999; Mathews et al, 2014). The transplant also requires a major financial expense, as a result, preventing the birth of a child who is impacted is a viable and realistic alternative (Colah et al, 2017).

There are numerous Indian institutions, as well as social groups (Rotary Clubs, Lions Clubs, etc.) and various NGOs and Thalassemia Parents-Patients societies, from a few decades have been undertaking education and awareness programmes regarding thalassemia, but, despite all these efforts, awareness of thalassemia among pregnant women participating in a multicentre was very low (Mohanty et al, 2008). The disease has adverse effects not only on the patients' but also their caregivers, psychologically, socially, economically, which creates lots of burden on

them too. Caregivers are people who help people in distress or when they are sick. Their importance becomes clearer in chronic disorders such as thalassemia. Caregivers' understanding of thalassemia is one of the most important aspects of disease prevention, patients' as well as caregivers' quality of life, good illness knowledge, provide better care to his or her ward, contributes significantly to community awareness of the disease (Biswas et al, 2018)). The purpose of this study was to determine the level of knowledge/awareness of thalassemic children's caregivers regarding the thalassemia disease and its management.

Materials and Method

The research was carried out in Chandigarh and Patiala, Punjab, among the caregivers of transfusion-dependent thalassemia patients who visited the Post Graduate Institute of Medical Education and Research (PGIMER) in Chandigarh and Rajendra Hospital in Patiala, Punjab. Many of the patients visiting these institutions were from adjacent Punjab states in North India, so the ethnicity of the study participants were diverse. A total of 105 caregivers were approached, and informed consent was gained from each of them prior to the interview using a pretested structured interview schedule. The interview schedule contained both closed-ended and open-ended questions to assess the participants' knowledge about practise of the thalassemia disease and its management, as well as their socio-demographic data. For the benefit of the participants, the interview schedule was translated from English to Hindi and Punjabi. We used an updated version of Kuppuswamy socio-economic scale 2012 for the year 2020, as amended by Saleem and Jan (2021). The caregivers' socio-demographic features, such as religion, education, occupation, family income, and the patients' sex, were also considered.

The caregivers' awareness of thalassemia was assessed using three portions of the knowledge section of the interview schedule. The first portion consisted of 11 questions about 'knowledge about thalassemia disease in general,' such as the causes and kinds of thalassemia, accessible screening procedures, and iron excess problems. The second segment contained five questions about thalassemia treatment, such as blood transfusions, iron load monitoring, infections, and so on. The caregivers' awareness of available thalassemia treatments was discussed in the third part. The scoring system utilised in the current study was established and adjusted on the basis of Biswas et al (2018) scoring system to assess caregivers' general knowledge and awareness. For the first two sections (as mentioned above), the caregivers' awareness score was computed by assigning a minimum score of '0' to each wrong knowledge/unawareness and a maximum score of '1' to each correct knowledge/awareness. The third section's scoring ranged from '0' to '5,' with '0' denoting "no awareness of any treatment option," "1" denoting "just one treatment option," "2" denoting "two options," and so on. As a result, each individual's 'total knowledge score' was computed by summing the scores from all three areas, with '0' being the lowest and '21' being the highest. In this case, a higher knowledge score showed a greater understanding of thalassemia.

Statistical analysis

The findings were rendered in the form of graphs and tables using MS Excel and IBM SPSS version 20. The Pearson correlation was utilised on scale data to determine the relationship between knowledge about thalassemia and socio-demographic characteristics such as SES and education. All of these analyses were statistically significant with a 'p' value of less than 0.05.

Results

In this study caregivers of total of 105 thalassemia patients were interviewed regarding their awareness and knowledge about thalassemia. The mean age of the thalassemic offspring (patients) of these caregivers was about 18 years with minimum being 8 years and maximum age as 39 years. Among 105 patients, 68.6 % were male and 31.4 % were female patients, who belonged to Hindu (53.3 %), Sikh (34.3 %), Muslim (10.5 %) and Jain (1.9 %) religions (Table 1). Table 1 also reflects the socio-economic characteristics of the caregivers of the present study. Among caregivers of patients, education of the fathers' ranges from primary to higher education (above graduation) where 8.6 % of them were illiterate; majority of them were Intermediate (26.7 %), followed by graduation (16.2 %), high school (16.2 %), middle school (16.2 %), primary School (8.6 %) and higher/ professional degree (7.6 %) level education. However, among mothers' of patients, the illiteracy rate was 12.4 % higher than the fathers, and majority of them were educated at high school level (24.8 %), followed by graduation (19.0 %), middle school (19.0 %), intermediate (12.4 %) and primary school (12.4 %) level education. The higher education level among mothers was up to graduation only. The occupation of the head of the family was noted under categories as mentioned in Kuppuswamy SES scale 2020, and it was found that majority of them were Farmers or Skilled agricultural workers (33.3 %), followed by elementary occupation/unskilled workers (12.4 %), semi-skilled workers (9.5 %), Skilled/trade or craft workers (9.5 %), Highly skilled/ Shop owners/market sale workers/Lower division clerks etc (9.5 %), and Legislators/high level administrators/senior officials/ big businessmen (9.5 %). Other occupations were also reported in comparatively lower frequency among caregivers' families such as semi-professionals/agricultural business/upper division clerks etc (5.7 %), technical/ associate professionals (5.7 %), and high professionals/officers/managers etc (4.8 %). The Family monthly income of the caregivers were also recorded as per the information provided by them and categorised according to Kuppuswamy SES Scale 2020, the mean family monthly income was found to be around INR 61604.76 ± 5554.83, ranging from minimum monthly income INR 5000 to maximum up to INR 3,00,000. Majority of respondents (35.2 %) had family monthly income between INR 49962 – 74755, followed by respondents fall in income categories INR 10002 – 29972 (18.1 %), ≤ INR 10001 (15.2 %), INR 99931 – 199861 (9.5%), INR 29973 – 49961 (8.6 %), INR 74756 – 99930 (7.6 %), ≥ INR 199862 (5.7 %) (Table 1).

Table 1
Socio-demographic profile of caregivers of thalassemia patients

S.No.	Socio-demographic variables (N = 105 for each)	Sub-categories	Percentage
1	Distribution of caregivers according to sex of their Thalassemic Child	Male patients	68.6
		Female patients	31.4
2	Religion	Hindu	53.3
		Sikh	34.3
		Muslim	10.5
		Jain	1.9
3	Education Father	Illiterate	8.6
		Primary	8.6
		Middle School	16.2
		High school	16.2
		Intermediate	26.7
		Graduation	16.2
		Higher Degree/ Professional education	7.6
4	Education Mother	Illiterate	12.4
		Primary	12.4
		Middle School	19.0
		High school	24.8
		Intermediate	12.4
		Graduation	19.0
5	Occupation of Head of the Family	Elementary occupation / Unskilled worker	12.4
		Semi-skilled worker/ Attendant/ machine operator etc	9.5
		Skilled workers/ trade or craft workers etc.	9.5
		Skilled agricultural workers/ Farmers etc	33.3
		Highly skilled workers/Shop Owners/Market sale workers/Lower div. clerks etc.	9.5
		Semi Professionals/Agricultural Business/Upper div. clerks etc.	5.7
		Technical/ Associate Professionals	5.7
		High professionals/ Officers/ Managers etc.	4.8
		Legislators/ High level Administrators/ Senior officials/ Big Businessmen etc.	9.5

6	Family Monthly Income (in INR)	< or = 10001	15.2
		10002 – 29972	18.1
		29973 – 49961	8.6
		49962 – 74755	35.2
		74756 – 99930	7.6
		99931 – 199861	9.5
		> or = 199862	5.7

The socio-economic status of caregivers was evaluated on the basis of Kuppuswamy SES Scale 2020, and it was observed that 46.7 % of caregivers belonged to lower middle SES level, 21.0 % to upper lower SES, 18.1 % to upper middle, 8.6 % belongs to upper SES and only 5.7 % belongs to lower SES level (Fig 1.). The mean of Kuppuswamy SES score was calculated as 13.92 ± 0.63, with minimum score 4 to maximum score up to 29 among the respondents.

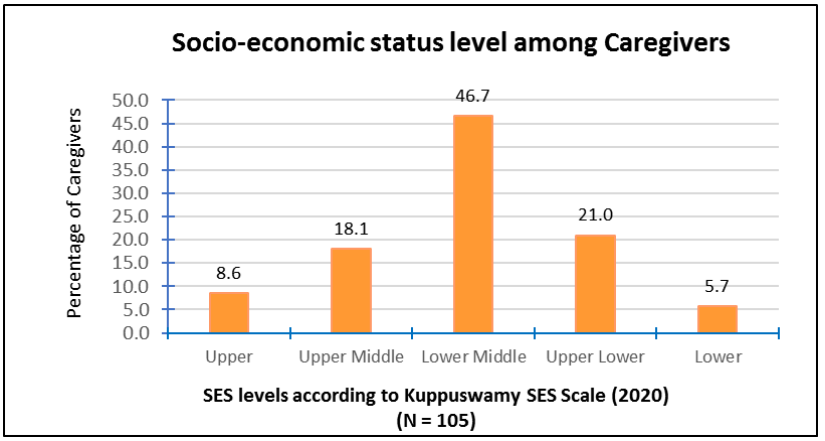

Figure 1. Socio economic Status among Caregivers of thalassemia Patients

When awareness among the caregivers of the patients was analysed, it was found that only 43.8% knew about the genetic diseases and 50.5% of the caregivers had knowledge that thalassemia was a genetic disease. About 81.9% of the caregivers knew that thalassemia was a treatable disease but couldn't be cured. 78.1% of the caregivers were aware that the carriers of the thalassemia disease could lead a normal life. The majority of caregivers (72.4 %) had knowledge that thalassemia major baby may born due to defect (genetic inheritance) in both the parents, 65.7% were aware about the premarital screening of the disease, 51.4% of the caregivers had known about the antenatal screening of the condition, and 42.9% knew that prenatal diagnosis of thalassemia was possible. When asked about consanguineous marriages, only 28.6% of the caregivers were aware that consanguinity played a major role in increasing the burden of the diseases like thalassemia. Majority of the caregivers (83.8%) had the knowledge of iron overload among the thalassemia patients, and 81.0% had the awareness that iron overload could lead to a most of the complications in thalassemia patients.

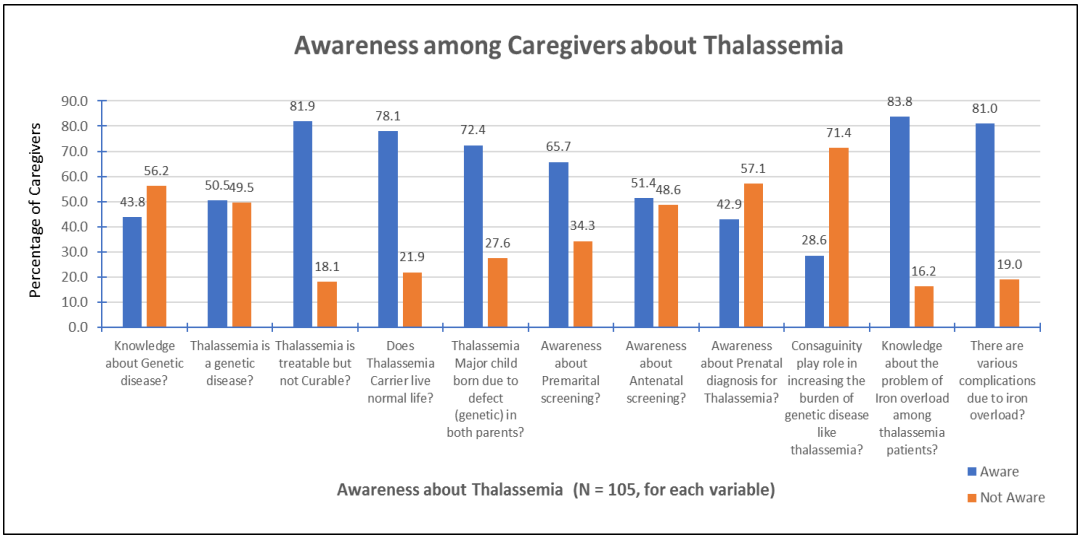

Figure 2. Awareness among Caregivers about thalassemia disease (in General)

When the caregivers of the thalassemia patients were asked what efforts needs to be taken to manage or treat the thalassemia disease, all the caregivers knew that it could primarily be managed through blood transfusion and all were also aware that blood transfusions could have potential reactions and complications in the patients. When asked about the awareness of the indications of splenectomy in the thalassemia patients, all the caregivers affirmed that they were aware of it. Further, 80.0% of the caregivers were also well aware of the iron chelation method as the prevention and treatment of iron-overload in the thalassemia patients, and only 43.8% of them had the knowledge that ferritin and T2MRI monitoring were important factors for the management of the disease.

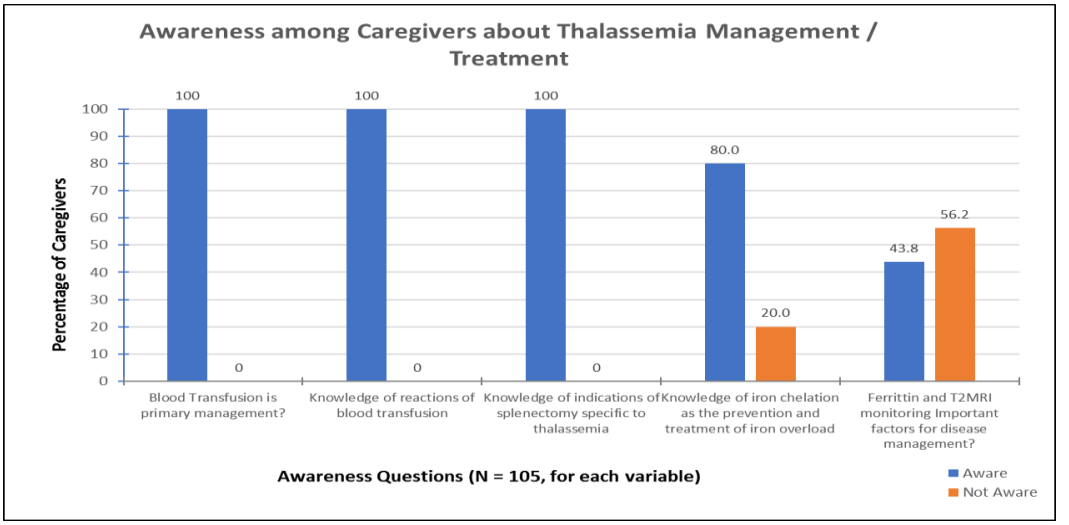

Figure 3. Awareness among Caregivers about thalassemia disease management / treatment

When the caregivers were asked about their knowledge regarding available treatment options for the thalassemia patients, collectively total five options were specified by different caregivers such as; Blood transfusion, iron chelation, splenectomy, bone marrow transplantation, and hydroxyurea therapy. However, some of them suggested only one, some suggested two or more options for the treatment modalities, these responses are depicted in the form of graph shown in Fig 4. In the figure it is seen that 15.2% caregivers suggested only blood transfusion as treatment modality option for the thalassemia patients, 25.7% caregivers mentioned two options (blood transfusion and iron chelation therapy), 27. 6% of the caregivers specified three options (blood transfusion, iron chelation therapy, and bone marrow transplant), and only 8.5% suggested all five options (blood transfusion, iron chelation, splenectomy, bone marrow transplantation, and hydroxyurea therapy) as treatment options for thalassemia.

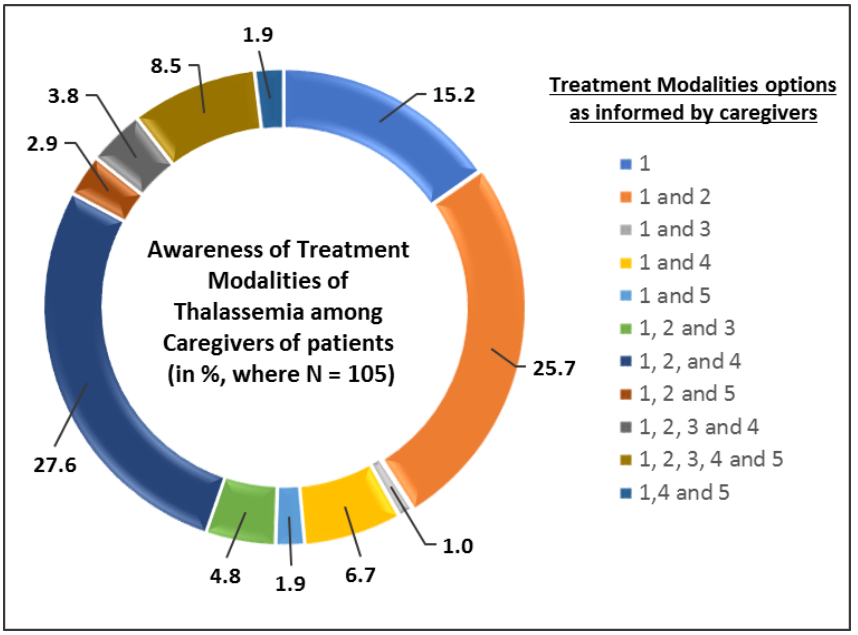

Figure 4. Awareness of Treatment Modalities of Thalassemia among Caregivers of patients

Note: here the codes represented in the graph are as follows;

Codes	Treatment Modalities for Thalassemia
1	Blood Transfusion
2	Iron Chelation
3	Splenectomy
4	Bone Marrow Transplantation
5	Hydroxyurea therapy

Table 2
Association of total knowledge score of caregivers with Socio-demographic factors

Variabes for Correlation		Education Father	Education Mother	Kuppuswamy SES score 2020	Age of Patients
Total Knowledge Score of Caregivers regarding Thalassemia (N = 105)	Pearson Correlation	0.454**	0.354**	0.366**	0.04
	Sig. (2-tailed)	< 0.0001	< 0.0001	< 0.0001	0.66

**. Correlation is significant at the 0.01 level (2-tailed).

The total knowledge score of the caregivers was calculated by adding the score attained for each knowledge variable where higher score indicated a higher level of knowledge regarding thalassemia, with the mean score as 13.61 ± 0.31. As knowledge and awareness may depend upon many factors, correlation was established between knowledge score of the caregivers and socio-demographic factors represented in Table 2. It was found that the total knowledge score had a highly significant positive correlation with educational score of both father and mother, and socio-economic score (Kuppuswamy SES 2020) with a p-value <0.01. However, it shows non-significant but positive correlation with the age of the patients.

Discussion

This study addresses the knowledge and practices among the 105 caregivers of the transfusion dependent thalassemia patients who came for regular visits to the medical facilities. As many patients visiting the hospital facilities in Chandigarh and Patiala, Punjab came from adjacent states such as Himachal Pradesh, Haryana, J&K, and the UP borders, it reflects North India as a whole. The interview-schedule method was used to gather information from the caregivers, all parents in the study, regarding their awareness about the disease and its management. The mean age of the patients was 18 years, with 68.6% male and 31.4% of female patients. The findings of this study were supporting the similarities in the studies done by Singh et al (2019), Bandyopadhyay et al (2003); Shukr et al (2011); Yagnik (1997) , where male thalassemia patients were more than their female patients. Out of total respondents, majority were Hindus, followed by Sikhs, Muslims, and the rest were Jains in minority. The socio-economic status (Fig 1) of majority of the caregivers was middle class (64.8 %) specifically lower middle, followed by the lower-class SES (26.7 %), which is in concordance with Singh et al (2019). The educational status of the majority of the caregivers (both the parents) of patients were of intermediate level, some were graduates and above, the literacy rate for fathers was 91.4 % and for mothers was 87.6 %. In present study the main occupation reported by the participants was diverse but majority of them belongs to Agricultural background, followed by skilled workers and small and big business (Table 1).

In terms of assessing caregivers' knowledge and awareness of thalassemia, our findings are similar for the variable 'thalassemia is genetic disease', to those of Biswas et al (2018) (47.6%), Saxena et al (2017) (47.5 %), Ishaq et al (2012) (44.6 %), and Maheen et al (2015) (55.2 %). Meanwhile, the awareness for the same among caregivers is higher than that of Ishfaq et al (2013) (5 %), Goyal, Hpapani, and Gagiya (2015) (15.0 %), and Arif et al (2008) (15.0 %), but lower than that of Ali et al (2015) (82.0 %), Inamdar, Inamdar and Gangrade (2015) (68.5 %), and Aggarwal (2016). (60.2 %). However, in some form or other the caregivers of this study had knowledge that thalassemia child are born due to defect in both the parents (72.4 %), however many of them (56.2 %) were not aware of the term 'genetic' directly, which is comparable with the above studies reported with higher awareness regarding the same.

Premarital screening, antenatal screening, and prenatal diagnosis (PND) are the three main strategies for preventing thalassemia births, particularly those of homozygotes. Premarital thalassemia screening in the general population detects thalassemia carriers and major. Because thalassemia is a hereditary autosomal recessive blood disorder, avoiding marriage between two thalassaemic individuals could prevent the birth of a thalassemia major kid at an early stage. If the couple did not undergo premarital screening, they can be screened for thalassemia after marriage through antenatal screening (during the first trimester of pregnancy) and prenatal diagnosis of the foetus (if both partners are thalassemia carriers) to avoid the birth of a major kid. In this study, 65.7 % and 51.4 % of caregivers were aware of premarital and antenatal screening, respectively, which was higher than Biswas et al (2018) (52.4 % and 50.9 %) and Inamdar, Inamdar, and Gangrade (2015) (31.4 % and 45.0 %), but lower than Ishaq et al (2012) (84.3 % and 76.5 %) and Kalra et al (2019) (100% for both) respectively. However, only 42% of caregivers were aware of PND in the current study, which is lower than the 67 % found by Singh et al (2019) and 76.5 % reported by Ishak et al (2012).

In a study conducted in Amritsar, Punjab, Kalra et al (2019) looked at caregivers' knowledge of thalassemia management and found that 100% of caregivers were aware that blood transfusion is the primary treatment and that transfusion might cause responses and infections (HIV, HBsAg, HCV, etc), which was similar to findings of the present study. However, according to Singh et al (2019), Biswas et al (2018), and Saxena et al (2017), about 77 %, 75.9 %, and 62.5 % of caregivers, respectively, were aware of the requirement for blood transfusion to maintain Hb levels. However, if not treated or managed properly, repeated blood transfusions can lead to major complications such as iron overload, which is the accumulation of excess iron in the tissues and various organs (spleen, liver, cardiac, head, etc.) of the body, causing problems in their normal functioning and, in some cases, it may lead to organ failure or removal of the organ (Angelucci et al, 2008). In the current study, more than 80.0 % of caregivers are aware of iron overload and associated complications, which is greater than the Saudi Arabian study (Alqarni & Algiraigri, 2021) which found that just 40% of caregivers were aware of the condition.

According to the Thalassemia management guidelines (Cappellini et al, 2021), thalassemia patients should have their spleens removed (splenectomy) if they have hyper-splenomegaly with symptoms like left upper quadrant pain or early

satiety, as well as increased iron overload due to increased blood requirements despite iron chelation therapy. During the patient's thalassaemia care, the size of the spleen should be thoroughly examined and recorded during the physical examination and, if necessary, by ultrasound. In the current investigation, all caregivers are aware of the primary indications for splenomegaly and splenectomy; Kalra et al (2019) found similar results.

Iron overload, which is one of the major difficulties among thalassemic patients, must be managed and controlled in order to maximise their survivability or lifespan. Thus, regular monitoring of ferritin levels and T2*MRI of patients can help to assess and manage excess iron in the body by treating with iron chelation therapy, which aids the body in excreting superfluous iron. In a study conducted by Singh et al (2019) among caregivers of thalassemic patients in Patiala, Punjab, it was discovered that 61 % were aware of the importance of ferritin monitoring, which is higher than the current study's findings. Iron chelation therapy, on the other hand, is the sole way to prevent and treat iron overload. In the current study, more than 80% of caregivers were aware of this fact about Iron Chelation Therapy, which is almost in line with Biswas et al (2018), findings (75.9%), lower than Kalra et al (2019), findings (100%), and higher than Singh et al (2019), reported (60 %).

Analogously, Biswas et al (2018), Inamdar, Inamdar, and Gangrade (2015), and Goyal, Hpapani, and Gagiya (2015), assessed caregivers' knowledge of thalassemia disease treatment modalities in Eastern India and discovered four different treatment options were specified by them, including blood transfusion, Iron Chelation Therapy, splenectomy, and bone marrow transplantation. Some people had only one option, while others had two or three, and so on, but only 7.6% were oblivious of any of them. However, several caregivers in the current study stated hydroxyurea therapy in addition to the foregoing possibilities, and all caregivers were aware of at least one treatment option, namely blood transfusion.

Studies like Ghazanfari et al (2010 and Biswas et al (2018) indicated a substantial relationship between caregivers' educational level and their knowledge of the disease, which is comparable to the findings of the current study, where we observed a positive correlation between the scores of these factors. This suggests that the greater the educational status of caregivers (parents), the more likely they are to be aware of thalassemia sickness. The reason for this discovery could be that as their educational level rises, so does their counselling readiness, and their knowledge retention. However, this is in contrast to the findings of Williams, Saraswathi and Lissa (2017), who found no such link.

In the current study, caregivers with a better socio-economic position were more likely to have more information of the disease, which was similar to Biswas et al (2018) findings. It differed from the findings Williams, Saraswathi and Lissa (2017), who found no such link between family monthly income and caregiver's expertise. The conclusion could be explained by the fact that a caregiver from a higher socioeconomic class is more likely to be educated and informed, and vice versa. Among various other factors that influence the knowledge, attitude and practices of the thalassemia patients and their caregivers, place of stay, rural or urban, also play a part, as study from Chawla et

al (2017) show that the people from the same community living in different setups can have impact on the management and awareness of the thalassemia disease.

Conclusion

Caregivers must have a thorough understanding of thalassemia and how to manage it in various illness states. In the present study, the awareness of the disease in terms of heredity, premarital screening, antenatal screening, prenatal diagnosis risk due to consanguinity, were lower than the awareness about treatment, carriers leading a normal life, genetic defect in both the parents leading to thalassemia major baby, iron overload, and complications in thalassemia patients due to iron overload. The treatment and management of the disease, all of the caregivers knew that it could be managed through blood transfusion, blood transfusions lead to health complications in the patients, indication of splenectomy, comparatively lower knowledge of management was found among the caregivers about iron chelation method, and still low awareness about the ferritin and T2MRI as management options for the disease. The total knowledge score was found to have a strong positive relationship with father and mother's educational scores, as well as socioeconomic status. Hence, the gaps in the knowledge of caregivers of thalassemic children should be addressed at every opportunity by scheduling regular counselling sessions and awareness-raising efforts in an easily understandable manner.

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Conflict of interest

Authors declare no conflict of interest.

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