

## Hierarchy of Iranian Parents' Information Needs and Social Seeking Behavior of Infants Suffering Blood Disease

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**Abstract:** Blood diseases are the most common of the hereditary disorders and are found in nearly all races. In Iran, overall prevalence trait is 3-4% of the whole population. The aim of this study is the identifying of Iranian parents' information needs and social seeking behavior of patients suffering of one of these blood diseases. This study was conducted on parents of infants who had been hospitalized in in hospitals affiliated to Semnan University of Medical Sciences in Iran in 2014. A valid, reliable and researcher made questionnaire used to collect data. The findings showed that the parents more preferred (Mean = 3.32) to learning about financial issue. In the construct of occasion of informing, the parents preferred (Mean = 3.79, SD = 0.40) gaining knowledge in the pre-marital stage. Dissemination of information via caregivers, media and medical information systems would mobilize social support for this group of parents.

**Key words:** Parents, information needs, social seeking behavior, blood disease, caregivers

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### INTRODUCTION

Blood disease is the most common of the hereditary disorders and is found in nearly all races. In Iran, overall prevalence trait is 3-4% of the whole population (Amin *et al.*, 2013). Blood diseases are among the most prevalent of chronic hereditary diseases having an extensive impact on the affected child, the family and the health system as a whole (Sapountzi-Krepia *et al.*, 2006). The symptoms of the disease are wide ranging from thalassemia minor with mild anemia and hypochrom microcytic anemia with no clinical symptoms on the one hand to thalassemia major with severe anemia on the other requiring multiple blood transfusions in the first year of life (Nemeth, 2013). Thalassemia major directly impacts different body parts including the cardiovascular organs, liver, kidneys, brain, secretory glands and the skeletal system (Shargian-Alon *et al.*, 2014). Thalassemia children are faced with physical and psychological problems that affect their quality of life (Messina *et al.*, 2008). Most parents adapt themselves successfully with their child's chronic disease but there are others who are unsuccessful probably due to a lack of correct awareness of the disease and suitable supportive sources (Imdad *et al.*, 2010; Mehdi *et al.*, 2011).

Results of researches have shown that Iranian parents need to be trained with regards to the essence of their child's disease, its cure and their child's diet; plus most of them displayed problems to deal with disease of their children (Madadi, 2001; Mahboobe *et al.*, 2012). Aydinok *et al.* (2005) have also done a study in Turkey on the psychological and social problems that thalassemia major children face there. The study concludes that instead of being worried about the disease itself, the children and their children were more worried about the cure and that they badly needed psychotherapeutic support. The results of researches in Iran have shown that because of the many problems the disease entails, Iranian children were faced with disorders that have badly damaged their quality of life (Madadi, 2001; Naderi *et al.*, 2012). In conclusion, the researcher suggests that adequate attention must be paid to the needs of these children and their parents. Thus, the parents of such children need to be given important information that would help them manage and solve the problems and predicaments faced by their children and themselves. They need timely, related, reliable and easily comprehensible information (Simon, 2011; Safavi *et al.*, 2012). Such health information is part of a necessary strategy for any health care organization (Kahouei *et al.*, 2014a-c) that wants to promote children caring for

themselves, choosing type of therapeutic regimen, cooperation of patient and family in clinical decisions, managing chronic disease and raise the level of health-related knowledge of the children and parents (Ali *et al.*, 2012).

Although, many studies have been undergone on thalassemia from different aspects yet none of them have studied and prioritized the parents' preferences of children with thalassemia major to receive information in developing countries. Thus, the question arises that what kind of information parents first look for and when and how they prefer to receive this information. Paying attention to the information needs of the parents is as important as the needs of the children. By considering the preferences of parents for health information, the way of dissemination of information (Kahouei *et al.*, 2014a-c) and offering assistance can be reformed and improved (Kahouei *et al.*, 2015a). From this perspective, the results of the present research facilitate an increase in utility and effectiveness of education of the parents and thus are a positive step toward the sustained health of major thalassemia children through correct planning. This research has been undergone with the aim of identifying of Iranian parents' information needs and social seeking behavior of thalassemia patients.

**MATERIALS AND METHODS**

The present research is a descriptive study done on parents (n = 53) with children having major thalassemia disease in a hospital affiliated the Semnan University of Medical Sciences in 2014. The census method was used in this study in a way that the parents of all the children hospitalized for major thalassemia in the pediatric ward of the hospital were included in the study. The instrument of research was a questionnaire designed by the researcher on the basis of extensive investigation of scientific texts and articles. The questionnaire consisted of two parts, the first including demographic information, like gender, relationship with patient, age, education and occupation whereas the second part contained 17 questions related to the parents' preferences in different constructs including: transmission of the disease, present problems, treatment, occasion of informing, notifying the parents and means of informing. In these section, the parents were asked to prioritize their preferences with regards to the questions by using numbers 1-4. To identify content validity, the questionnaire was evaluated for suitability and reliability by clinical experts and their views were used in rewriting the questionnaire. At the end, the questionnaire consisted of 22 questions. The Cronbach Alpha (0.87) was used to confirm the reliability of the questionnaire. It must be noted that the individuals who

participated in the pilot study were excluded from the sample population. The present research was undergone after initial permission was acquired from the Ethics Committee. The parents were informed of the goal of the research and those who were willing to participate in the study were assured of confidentiality of data. Then, the sample population was given the questionnaire. To determine the distributions of responses, SPSS was used to perform descriptive statistics.

**RESULTS**

The results indicated that 56.6% were male, 35.8% were employee, 24.5% had not finished schooling (Table 1). The 75% of the samples preferred being informed of the prevention methods of the disease as first priority. With regards to problems being faced in the disease, the parents more preferred (Mean = 3.32) to learning about financial issues (Fig. 1). In the construct of occasion of informing, the parents preferred (Mean = 3.79, SD = 0.40) gaining knowledge in the pre-marital stage. Concerning notifying to treatment, the parents preferred (Mean = 3.50, SD = 0.57) to know about the side effects of drugs (Table 2). On the subject of means of acquiring information on thalassemia. The parents preferred (Mean = 3.40) would rather get it from television. (Fig. 2).

Table 1: Demographic characteristics

Characteristics	Group	N (%)
Parents	Male	30 (56.6)
	Female	23 (43.4)
Age	20-29	13 (24.5)
	30-39	29 (54.7)
	40≤	11 (20.8)
Job	Unemployed	16 (30.2)
	Employee	19 (35.8)
	Other	18 (34)
Education	Uneducated	13 (24.5)
	Diploma	31 (58.5)
	Bachelor degree	9 (17)

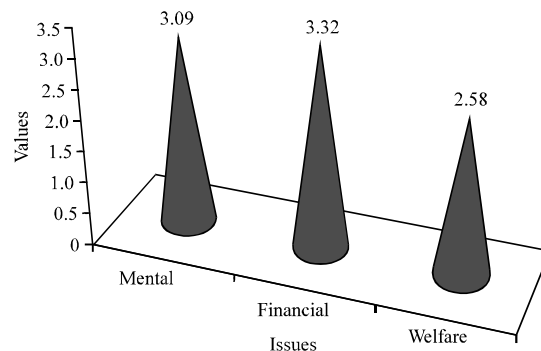


Fig. 1: Mean of parents' information needs related to problems, p<0.05

Table 2: Parents' information needs

Information needs	Mean±SD	p-values
<b>Mode of transmission of the disease</b>		
Inheritance	2.77±0.82	0.123
Disease prevention	3.16±0.82	
<b>In relation to the care</b>		
Proper diet	2.84±0.79	0.001
Drug complications	3.50±0.57	
Child activity	2.60±0.79	
<b>Time of informing</b>		
Prenatal	3.79±0.40	0.001
Before pregnancy	3.20±0.40	
<b>Informing to parents</b>		
Father	3.56±0.50	0.336
Mother	3.43±0.50	

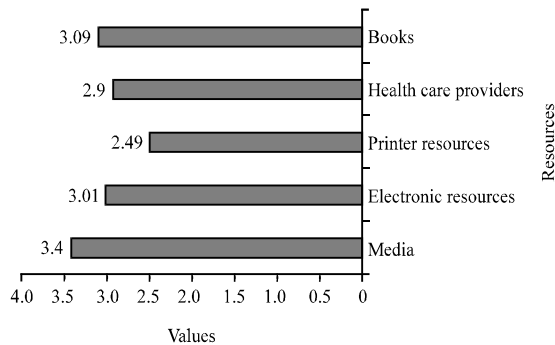


Fig. 2: Mean of parents' social seeking behavior, p<0.05

## DISCUSSION

The results of the research show that in order to prevent the emergence of the disease, the parents primarily preferred to gain information on how to avoid having thalassaemic children. The findings of a study in Iran by Sadaghiani and Farshid (2001) concluded that although, most couples had a positive picture and attitude to the problem of thalassaemia in theory, they did not have suitable precautionary practices. A research by Ahmed *et al.* (2002) focused on viewpoints and behavior of carriers and found that the samples under study had little or no knowledge regarding carriers of the disease or of how the disease could be passed down through genes. The results of this research once again highlight the need for raising awareness with regards to prenatal screening which is an effective measure in detecting any anomaly during the embryonic stage (Li *et al.*, 2006; Lau *et al.*, 1997).

Moreover, the findings of our research show that the parents preferred to receive this kind of knowledge in the prenuptial stage. A study by Khaleghinejad *et al.* (2009) confirms the same; it concludes that Iranian parents preferred to get training in premarital counseling classes. This reflects the fact that the parents consider premarital screening as a necessary step in the prevention of the disease. It also seems that because some had been

inadequately informed about pre-marital training which bars prevalence of the disease, they preferred to receive knowledge in the pre-pregnancy stage. Other studies have shown that nearly all Iranian couples need guidance and direction in order to control birth and to execute family planning (Motlaq *et al.*, 2013; Hashemi and Salehi-Isfahani, 2013). The results of this study shed light on the utmost importance of designing training courses and making extensive use of teaching aids and multimedia in order to eliminate misinformation and wrong beliefs in couples and help them choose a suitable method to prevent the birth of a thalassaemic child.

In the construct of present problems, our findings show that in the parents' endeavor to improve the quality of life of their child, the parents felt economic pressure and this caused them to give priority to learning about economic problems first. Moreover, literature on this subject has shown that due to the chronic nature and the medical expenses of the disease, economic problems are to be seen in Iranian parents with thalassaemic children in a way that they are worried about the schooling, occupation and recreational affairs of their offspring (Madadi, 2001; Ali *et al.*, 2012). It seems that teaching methods to overcome crisis situations could be beneficial as the parents play a positive role in helping and supporting the patient; moreover, having thalassaemia is not only a significant condition for the patient but also for the parents (Yazdi, 2007).

It seems that the feeling of hopelessness, anxiety and depression among the parents causes some of them to prefer gaining knowledge in the field of psychological problems involved with the disease first. A study by Rao *et al.* (2004) is in line with our findings. It concludes that the parents of children with thalassaemia suffer more from psychological problems. The findings show that the parents of thalassaemics are affected by the various problems they face so much so that the suffering from the disease and the worries regarding their child's future makes their life difficult. This is because of the fact that Thalassaemia like most chronic diseases pushes the individual towards psychosocial problems. A research by Yazdi (2007) concluded that a fear of exacerbation of their child's disease and anxieties about their child's future are the major psychological concerns of the parents.

The results of our study have shown that since fathers accept the reality of the disease more easily and lead the way in explaining the child's disease (Safavi *et al.*, 2012), families prefer that the fathers be informed of the disease first. Other studies have shown that the fathers pay attention to and feel responsible for the medical, rehabilitation and educational expenses. They can adapt and understand their child's illness more easily

and so face less psycho-social problems, moreover they deal both with the material aspects as well as the realities on the ground (Hildenbrand *et al.*, 2015; Oers *et al.*, 2014). However, our findings contradict the results obtained by Heaman (1995) and Astedt-Kurki *et al.* (1999) that cite that the need for information in the mothers of thalasseemics is greater than that in the fathers. The reason for this difference in findings could be the fact that mothers are sentimental and emotional and might seek information more. Due to the fact that in major thalassemia both parents are carriers of the disease, they feel equally at fault for their child's disability and since they are both concerned about his or her problems, nearly the same need for information is seen in both (Hosiany and Reza-Zade, 2002). Thus, it seems important that correct plans must be designed for teaching them both.

It was found that information needs about food regimen of the child was priority some parents. It can be concluded that only a small number of parents have realized the importance of correct nutrition for their child. Perhaps the parents thought that thalasseemics just suffer from a iron deficiency. Whereas, contrary to general belief, they not only do not have a deficiency of iron but are in fact vulnerable to iron toxicity that could be detrimental as iron accumulates in various organs and can cause premature death (Nemeth, 2013). Therefore, it is necessary to provide the parents with the required information on food regimens suitable for their offspring. The findings show that some parents sought information on the side effects of drugs. This could be due to the fact that injecting this drug is difficult, time-consuming and painful. The results also show that the parents were worried about the side-effects that the medications manifested in their children such as problems of the heart, liver, diabetes and hypothyroidism. Because not injecting desferal or injecting it later with the start of blood transfusion increases the grounds for side-effects (Weissman *et al.*, 1997).

Our findings further show that some parents preferred to know of the activities and the behavior of their children to other things. It could be possible that the parents were worried by the signs of depression they saw in their child and the effect that it had on their child's quality of life. Another reason for the same is that thalasseemics have a lower level of self-confidence and social esteem and performance (Telfer *et al.*, 2005). Moreover, long absence from school, poor academic performance, feeling of hopelessness because of depending on others for care coming from the inability to do basic routines and limitations in social relationships, all in all can have harmful effects on the attitudes of both children and parents. On the other hand, the physical and

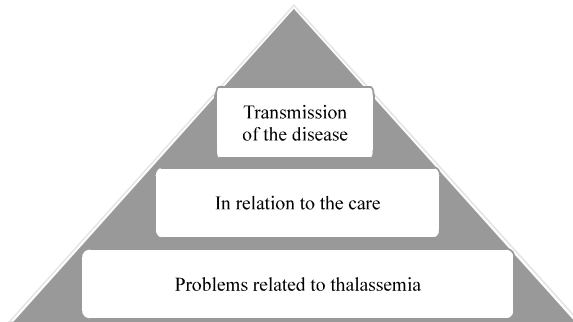


Fig. 3: The hierarchy of parents' information needs

psychological problems of the thalasseemics can result in a feeling of hopelessness, a decline in social performance, a disruption in social relationship with friends and in social isolation (Gharaibeh *et al.*, 2009). This ever more necessitates the provision of knowledge to help parents overcome socio-behavioral problems resulting from physical disorders in their thalasseemic children. This study indicates that the parents' information needs to be placed in a hierarchy. So that they prefer to access information to solve their mental, economical and welfare problems (Fig. 3).

The study subjects preferred to gain knowledge via media. Hajian study confirms our result as it concludes that Iranian couples named radio and television to be their main source for pre-marital information on thalassemia. The findings show that parents have a strong tendency toward gaining needed information from the public media as a valid and up-to-date media. As this source of information is easily available, it seems to be a good source of knowledge for parents. Salmah (1996), too has studied the same and found that utilizing public media devices and educational programs on thalassemia disease makes changes in the awareness constructs, especially of young people.

Further, some parents gave second preference in this field to information booklets. Kahouei *et al.* (2014a-c) in a study on women who underwent surgery have found that they preferred to receive information for post-surgery care through booklets. It seems that the advantages of booklets such as their small volume, portability and availability in all locations draw the parents to use this source of information. Nagler *et al.* (2010)'s study has also concluded that children wanted to receive information through booklets; reasons for the same being the chances of forgetting certain instructions and difficulty in using the computer.

Our findings showed that gaining information through the internet was of low priority among the parents. Although, this study did not check for the

obstacles in internet usage but previous research has identified reasons like no internet access, shortage of time, computer illiteracy and a lack of internet search skills as the main factors curbing internet usage in both parents and children (McMullan, 2006; Peterson and Fretz, 2003; Kleiner *et al.*, 2002). The findings of our research however reflect that internet has not yet become a common source for finding medical information by Iranian parents with thalassemic children. Considering the fact that awareness plays a major and constructive role in decreasing the prevalence of this disease, it is believed that using several information sources to transfer valuable knowledge to the parents will lead to an improvement of the health trend in society.

With regards to gaining information from clinical staff or caregivers, our findings show that this was not among the first priorities for most parents. Many studies contradict the same stating that parents chose gaining information from clinical staff as their top source of information (Schuster *et al.*, 2000; Kilicarslan-Toruner and Akgun-Citak, 2013; Knapp *et al.*, 2011). According to our results the main reasons that the parents looked for sources other than clinical staff were skepticism and lack of awareness of the duties of the caregivers. Thus, clinical staff should strive to make the parents believe that they have more knowledge related to the needs of the children and are more worried about the reactions and responses of the children than the parents (Beaver *et al.*, 2010). The results of this study can be useful for information systems designers. So, when designing an information system for this group of the population, they are informed information system content that can provide relative and useful information (Farzaneh *et al.*, 2011; Kahouei *et al.*, 2011) to the parents. Providing useful information by health care providers, the media and clinical information systems (Mozhgan *et al.*, 2012) leads to parents receive social support.

Dissemination of information via caregivers, media and medical information systems would mobilize social support (Mehdi *et al.*, 2012; Kahouei *et al.*, 2013a, b) for this group of parents. Moreover, the findings showed that about a fourth of the parents had not completed high school (12 years of education) indicating the importance of supplying parents with high quality information. Informational support will help the parents to better manage the sickness of their child and to improve their quality of life (Kahouei *et al.*, 2015b). Plus providing knowledge to this group in society would give them a feeling of being supported (Kahouei *et al.*, 2013a, b).

The results of this study should be interpreted with caution because the study was conducted using a researcher made questionnaire survey method and potential problems such as poor understanding of questions and probably bias answer threaten the results

of the study that is resolved with regard to questionnaire validity and reliability. Also, non-generalizable results of the study because of being done in a city is of the other limitations of this study. But however, the study results were in line with other studies in this field. Further, quantitative nature of this study limits the study capacity, so one cannot discover parents' experiences for their information needs. Also, further studies should be performed to determine whether unsatisfied information needs increase stress and anxiety of parents. Also what the most-effective methods are providing information to the parents and that how they can be supported in relation to their information needs.

## CONCLUSION

The results of this research showed that as the parents of children with thalassemia major want to care for their children in a better way, their main priorities for gaining knowledge on the disease ranged from disease transmission, present problems to the occasion and means of receiving knowledge about the disease. Further, they preferred to receive knowledge through conventional rather than electronic means. Undoubtedly social health is directly related to correct knowledge transfer to parents regarding the nature of the disease, prevention, effects and difficulties entailed, especially in such diseases that have a negative impact on the life of the individual in particular and on social wellbeing as a whole.

On the other hand, inculcating a cooperative and empathic culture in the country can lead to a reduction of isolation for the parents and aid in the rehabilitation of thalassemics. The result of this research can have important indications for caregivers and supportive units as it will increase their awareness regarding the needs of the parents and improve the quality of healthcare by solving the problems of the children and making training more effective for them.

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