Nurses' Knowledge and Role in the Management of Thalassemic Patients in Sulaimania Thalassemia Center

معارف ودورالملاك التمريضي في معالجة مرضى الثلاسيميا في مركز السليمانية للثلاسيميا

Pary M. Azize PhD, MSc, BSc, RN*
Farida A. K. Tahir MSc, BSc, RN **
Janet Kelsey MSc, BSc Hons, PGDip Ed, PGCEA, RSCN, RGN, RNT ***

*Instructor, Nursing Department, Sulaimani Polytechnic University, Sulaimania, Kurdistan Region, Iraq. E-mail: pary.azize@spu.edu.iq
**Assistant Instructor, Midwifery Department, Sulaimani Polytechnic University-Sulaimania- Kurdistan Region-Iraq. E-mail: farida_barwari3@yahoo.com
***Instructor, Portland Villas, Plymouth University, England. E-mail: Janet.Kelsey@plymouth.ac.uk

المستخلص:

الهدف: تقييم معرفة و دور الممرضات في معالجة مرضي الثلاسيميا ، استكشاف الاحتياجات التنموية لهيئة التمريض .

المنهجية : " استخدمت هذه الدراسة المنهج النوعي لاستكشاف مدى معرفة الممرضات حول مرض الثلاسيميا من خلال المقابلات الجماعية الغير منظمة و قد استمدت الأسئلة علي المراجعة المكثفة للدراسات السابقة.

النتائج : وتشير النتائج إلى أن الممرضات في اقليم كردستان العراق لهن دور محدود من حيث اتخاذ القرارات و هناك نقص في توثيق المعلومات السريرية من قبل الممرضات عدا تسجيل الحالات الغير طبيعية وتعتبر الممرضة نفسها غير مشاركة في التثقيف الصحي المستمر لمريض الثلاس يميا ولكذالك فالممرضة غير مشاركة في المساندة النفسية لمريض الثلاسيميا النتائج اظهرت ان معلومات الممرضات ذوات مؤهلات اقل الممرضات ذو ات المؤهلات الجامعية هي افضل من معلومات وبصورة عامة نقص عام في المعرفة التفصيلية في علم الجينات

التوصيات: يجب إجراء المزيد من الدراسات لتقييم دور الممرضة في اقليم كردستان و هناك حاجة كبيرة لتوجية و دعم التعليم والتدريب من أجل تمكين الممرضات لتحقيق هذه الاهداف . التعليم المستمر ضروري لتمكين الممرضات لتقديم الرعاية الجسدية والنفسية والتثقيف الجيني للمرضى و ذويهم .

Abstract:

The aim of this study is to assess nurse's knowledge and role in the management of thalassemic patients in the Sulaimania Thalassemia Centre.

Methodology: This study utilized a qualitative approach to explore nurses' knowledge about thalassemia through semi structured group interviews. Questionnaire was synthesized through a comprehensive review of literature.

Results:

The results show that nurses in Kurdistan region of Iraq have a limited role in terms of decision making and there is lack of nursing documentation other than that of recording abnormal events, and a lack of knowledge about and engagement in continuous training about the management of thalassemia and consider themselves not involved in initial or ongoing patient education; however they do have the role of explaining the risk of non-adherence to chelation drugs for the families. They consider themselves not supporting the patient's psychological state. The knowledge of nurses with a university degree in Kurdistan regarding thalassemia is much better than the knowledge of a nurse without degree. There is however an overall lack of detailed knowledge of the genetics of thalassemia. Further studies should evaluate the role of the nurse in Kurdistan. Guidance and support for further education and training is required in order to enable nurses to fulfill their potential.

Recommendations: Continuous education is necessary to facilitate the nurses to provide enhanced physical, psychological care besides the genetic enlightenment for the patients and their families.

Key words: Thalassemia, Nurses' knowledge, Nurses' Role, Nursing documentation, Communication skills

Introduction

Thalassemia is one of the world wide genetic hemoglobinopathies caused by a defect in the genes responsible for hemoglobin synthesis [1]. It is common among those of Mediterranean descent such as Greeks, and Italians and amongst those from Africa, Southeast Asia, Iran and Arabian Peninsula[2] Thalassemia is a recessively autosomal inherited condition demonstrating either decreased or absence of synthesis of one of the two polypeptide chains fractions (α or β) that form the normal adult human hemoglobin molecule. Its clinical severity varies from Thalassemia major, intermedia and minor with the description of the various forms based on the severity of the condition rather than the underlying genetic abnormality [3]. Thalassemia major usually is incompatible with extra uterine life; β-thalassemia major presents in infancy and requires life-long transfusion therapy and bone marrow transplantation for successful control of the disease [4].

Non - adherence is recognized as a serious problem in chronic diseases especially hemoglobin disorders which may lead to serious or fatal complications. In addition immigrant populations may face cultural and language challenges in their new communities, which may impede them from seeking appropriate care for their children with thalassemia [5]. The role of the nurse in promoting adherence is reported as being to clarify and explain both the complications of thalassemia and the effects of non-adherence to the chelation therapy [6].

First contact with the health care team is by nursing staff, it is therefore essential that they demonstrate excellent communication skills. Empathy and sensitivity are recognized as important attributes of the nurse in the management of the patient [7]. Clear communication gives the patient time to express feelings and fears, and for the nurse to provide support, encouragement and reassurance, thus enabling supportive feedback [8, 9]. The most important role of the nurse is to support the patient to have an active part in his /her own care [10]. Nursing can thus be seen to be helpful emotionally and intellectually and these two aspects require a sincere and natural commitment to fulfill the requirements of the patient, not only from the medical point of view but also psychologically [11]. Nurses complement medical staff in sharing information with the patient and this includes discussions re expectations of quality of life [12]. Hence they have to demonstrate understanding of the patients' needs and communicate appropriately using a language which can be understood [13] and being aware of boundaries in interactions with the patient [14].

Nurses also play a critical role in managing the patient's quality of life by helping to prevent unnecessary complications and providing treatment aimed at minimizing interference with the demands of school or work [15]. This encompasses e.g. instructing the patient and their family about the detection and reporting the serious symptoms such as fever or pain [16], clarifying the importance of cleanliness and encouraging interaction with other health professionals especially the psychologist [17]. Family support is considered essential in managing thalassemia and this is aided through maintaining regular and prompt contact [18].

The aim of this study is to investigate nurse's knowledge and role in the management of Thalassemia patients in Sulaimania Thalassemia Center.

The Objectives are:

1. To examine nurses' knowledge about thalassemia
2. To assess the role of nurses in managing the thalassemic patients

3. To explore the developmental needs of the nursing staff.

Methods

This study utilized a qualitative exploratory approach to examine nurses' knowledge about thalassemia through semi-structured group interviews in relation to care of patients with thalassemia. Questions were derived following a literature review [19]. A small set of open-ended questions were formulated, which enabled the researchers to fully explore respondent's responses and enabled them to gain clarification and meet the study aim.

Participants

Non- probability sampling was used to select purposive sample of participants who met the criteria of selection. Nine nurses were recruited, hence all the nurses in the center agreed to participate in the two interviews. The participants were of different educational levels: Five college and institute nurses (Graduate Nurses) were in the first group. The other four (A skilled Nurses) in the second group were nurses, their practice ranged from between 5 -20 years in working in the hospital with a secondary nursing school certificate.

Setting

The study was carried out in the Thalassemia Center, General Teaching Hospital- Sulaimania in Kurdistan region of Iraq.

Demographic data

Demographic data was collected using a short questionnaire completed by the nurses with their consent, regarding their age, gender, level and type of education, length of time working in the hospital and confirmation that they care for patients with thalassemia (table 1).

Data collection

Semi structured face to face interviews were carried out guided by a series of questions in order to ascertain knowledge of the participants (Appendix 1). The questions were validated by a panel of expertise. The interview questions were translated to the Kurdish language by the researcher and were reviewed by a few professional translators to validate the quality of the translation. Interviews lasted 45 minutes and were carried out in two groups. This enabled comparison between the level of knowledge of those degree educated but with less clinical experience (group 1) and those with more than five years clinical experience but less formal education (group 2). Official permission was gained from authorities in the hospital to carry out this study. Ethical approval is not a requirement in Sulaimania. However, participants were informed about the objectives of the study and the interview technique. The researchers also confirmed the nurses that there were no right and wrong answers in the interview and that their answers would not affect their employment. Thus informed consent was obtained. All participants were questioned by the same two researchers (Pary A. & Farida T.).

Analysis

Qualitative content analysis of the interviews and field notes was carried out to identify the main concepts of the study. Therefore, themes and sub themes were coded into categorical distinctions [20]. Some systematic ways were used such as, the researchers read the transcripts several times in order to organize the data and recognize themes and subthemes then margined the texts and referenced them under the relevant themes and sub themes. Data were transcribed in Kurdish then translated to English. The steps in the analysis were: (i) transcription of the interviews; (ii) analysis of the content of the data to enable identification of themes and coding; (iii) combining of the interview transcripts and notes to identify the emphasis or intensity of the participants comments and to differentiate between individual opinions and group agreement; (iv) re-listening to the audio files to ensure the adequacy of data.

The participants' data revealed three themes and within each theme 3-4 sub themes (Table 2). Numbers are noted for each participant (e.g. P2, P3, and P7). From P1 to P5 was Group One and consists of the nurses with diploma or college background (graduate nurses); whereas, from P6 to P9 was Group Two which are the non-graduate nurses. Data were excerpted for these themes from the conversation between the members in the group and are presented in the result section.

Table 1. Demographic data

Demographic data	Group1Graduated nurses (n=5)	Group 2 Assistant Nurse (n=4)	Total	%
Age				
25-30	4	0	4	44.4
30 above	1	4	5	55.5
Total	5	4	9	
Gender				
Female	5	4	9	100
Male	0	0	0	0
Total	5	4	9	100
Level of education				
College nurse	1	0	1	11.1
Institute Nurse	4	0	4	44.4
Ungraduated	0	4	4	44.4
Total	5	4	9	
Length of time working in hospital				
<2 years	4	0	4	44.4
2-5 years	1	0	1	11.1
6-10 years	0	1	1	11.1
>10 years	0	3	3	33.3
Total	5	4	9	
Have you received any theoretical or practical training during your work time about how to deal with thalassemia children?				
Yes	1	0	1	11.1
No	4	4	8	88.8
Total	5	4	9	100

Table 2. Themes and Coding

Code	Themes
1.	The role of nurses in the thalassemia center with the following sub themes:
1.1	Blood transfusions
1.2	Health education
1.3	Documentation
2.	The knowledge of the nurses in the Thalassemia Centre with the following sub themes:
2.1	Signs of thalassemia
2.2	Thalassemia health problem.
2.3	Investigations
2.4	Administration of drugs
3.	Knowledge deficit of the nurses in the Thalassemia Centre including the following sub- themes:
3.1	Type of Hb prevalent in thalassemia patient
3.2	The pathology of the disease
3.3	Investigations
3.4	Health Policy

Results

Various roles were identified by participants; one of the graduate nurses stated that she assessed patients' general health status. However, she says that when there is a major health problem she contacts the medical staff.

I assess the general health of the patient but when there is a problem which needs the intervention of a doctor I refer. I have my own code and every patient has a code and I send this information through the network (p1). (Each nurse and patient has a code (ID number) information is transmitted via a network to enable medical staff to review care. However, some participants said that patients were initially seen by both a doctor and a graduate nurse. *At the beginning the patient is seen by a doctor and graduate nurse and we follow their instruction (p3).* For example in blood transfusions, the nurse's role is to implement what the doctor orders.

The nurses do not see themselves to have a role in health education or psychosocial care. However one graduate nurse stated that; *I make relations with schools where there are large number of thalassemic pupils. And also with those who are recently married to give them advice (p1).* Hence, the role is limited; whilst carrying out clinical procedures the nurses acknowledged that they discuss issues with the patient and their family.

The nurses explain the risk of non-adherence to patients in order to encourage them to use chelation drugs as required. However, when patients do not comply they refer them with a social worker for further intervention.

We explain to the patient the risk of non-adherence and if the patient insists not to take the treatment, then we ask the help of a social worker. Besides we ask them to return back the empty vial (p4).

Most of the non-graduate nurses stated that they do not have paperwork for recording care. They record only abnormal events such as allergies due to blood transfusion, side effects of the chelation therapy and problems, but one of the graduate nurses stated that she can record her notes and has her own code. *After observing the investigations of the patient I complete a special check list according to the side effect of chelation therapy and I assess the general health of the patient then I send the patient information through the network (p1).*

All non-graduate nurses reported that they do not trust their knowledge or are not authorized by the doctor in the hospital to record care. Some did not agree with this limited role, while others said they are contented.

Most participants said that the doctor makes decisions about care; one graduate nurse stated that she does not have any role in making a decision about investigations. This leads the nurses to depend totally on the doctor's instruction rather than the utilization of their knowledge. However, when asked about ferritin levels, investigations, types of hemaglobin and prenatal tests they all had limited knowledge.

In assessing the knowledge of the nurses about the signs of thalassemia, non-graduates explained the basic signs of thalassemia. However, only one described the physical appearance of the patient: *They have large bellies, large heads, changes in the structure of the head and face bone, fatigue and dark skin (p7).* When asked about the complications of iron over- load, some graduates knew some complications and the normal level of some investigations,

such as ferritin. *By the estimation of serum ferritin iron overload can be revealed. The signs are: dark skin, fatigue, changes in the bones of the face and head (p1)*

When some participants in both groups asked about genetics they report that thalassemia is a hereditary disease which passes from parents to their children. It is a hereditary disease comes from the parents when they are carriers of the gene or at least one of them is thalassemic, the gene is responsible for the condition. However, most do not know how the gene is transmitted from parent to child. There was also inaccurate knowledge about the types of thalassemia as they mixed carriers with one of the types of thalassemia (intermedia*). If both parents were carriers, the children may have thalassemia minor. If both parents have thalassemia major 3 out of 4 of them will be with thalassemic.*

When questioned about new treatments available to treat children with thalassemia most but particularly graduate nurses knew about bone marrow transplant and genetic examination, but lacked detailed knowledge of these procedures. None of the participants knew of a follow up program available in the health care system in the Thalassemia Center in Kurdistan.

Discussion

Thalassemia is a major public health problem which can cause a psychosocial burden on the patient and family [21]. This is as a consequence of hospital visits for supportive lifelong treatment and the special care needed to have a good quality of life [22].

Our findings demonstrated that the patients in this Thalassemia Center are assessed first mostly by the doctor. The nurses think that they have a limited role in terms of making decision about care. The work a nurse is allowed to carry out is not necessarily dependent on their level of training and some have the same job description regardless of their level of training [24]. This is supported by the work of [23] who investigated the quality of health care services offered to the patients in Erbil governorate of Kurdistan region in Iraq. We found nurses in this Center acting in a limited role, which has the potential to affect the quality of care delivered.

The guidelines of the Thalassemia International Federation in the recent study, state that the patients meet nurses first and patients spend more time with them; therefore, they will have more confidence and trust in them [8]. However, particularly in the health education of thalassemic patients and their families, this study shows that the nurses have no role in educating the patients. This is at odds with the guidelines of the Thalassemia International Federation which emphasizes that the nurses' role is essential in helping patients to become experts in their own condition; teaching effective techniques for self-management, prevention of complications and successful transition of pediatric patients to the adult team of healthcare specialists. Nursing is regarded as both an emotional and an intellectual endeavor that requires a natural and sincere commitment to meet the needs of each patient, not just in terms of medical care but also their psychological well-being [25]. However, the results of this study demonstrate that the nurses do not have any recognized role in the psychosocial care of the thalassemic patient. As children with major thalassemia and their families have a psychosocial burden. Study showed that most of the patients with thalassemia major had severe psychosocial problems [26]. They concluded that psychosocial support should be provided by the nurses in order to support the children and families to cope with the disease and decrease the impact of the affected children on the family. In addition

nurses and health professionals are expected to engage with patients to explore the family's feelings, concerns and needs [27]. It has been stated that medical therapy of these patients should be supported with psychological aid and psychiatric treatment [28]. Therefore, psychologists, psychiatrists and nurses all have a vital role to support these patients psychologically to alleviate their distress. Thus the nurses' role in this Center is in conflict with these recommendations.

This study found that nurses in Kurdistan do have the role of explaining the risk of non-adherence to the chelation drugs for the families and the patients. However, if the patients or the families do not take the risk into consideration, the nurses will ask for assistance from social workers to talk to the families and the patients and inform them about the consequences of their actions. As the recent study stated there is a relationship between psychosocial status, knowledge about the disease and adherence to deferoxamine, therefore, systematic education for both patients and their families is essential to improve the quality of care [29]. This is supported by [30] who demonstrated the association between systematic education for patients and caregivers to improve adherence to treatment and the importance of practical knowledge for thalassemia major patients in order to advance their adherence to treatment

Nursing documentation has been one of the most important functions of nurses since the time of Florence Nightingale because it serves multiple and diverse purposes [31]. Current health-care systems require documentation to assess the quality of care and to ensure continuous care. In this Center the nurses have no nursing documentation, it is absent in the health system. As explored in the study about nursing documentation, it was found that there were three aspects contributing to the difficulties of documentation; disruption, incompleteness and inappropriate charting with limited nurse abilities; confidence and enthusiasm as well as ineffectual nursing procedures, insufficient nursing examinations or supervision and staff development all influence the ability of nurses to record the patient's progress and outcome [31]. The limited ability of the nurses in Kurdistan, in terms of documentation, is reported as partly due to the physicians who control most of the work as well as a lack of provision within the health system. Consanguineous marriages are more common amongst eastern global populations [32]; therefore, there is a need for genetic education and counselling. Yet these nurses have a knowledge deficit concerning genetics, which is supported by the study reports that nurses have insufficient knowledge of basic genetics and need additional education on the subject [33]. Furthermore in a study of two hundred nurses and midwives been assessed it was found that the majority (86%) had inadequate knowledge regarding genetic information [11]. An emphasis on genetic education and practice is therefore needed to ensure that health-related professionals become knowledgeable about genetic information [34].

Knowledge of the graduate nurses in this study is shown to be better than that of the non-graduate, however there is universal lack of knowledge about and engagement in continuous training about thalassemia and the health policy of the Center. These results can be seen across the health care system in Kurdistan. According to [35] there is a lack of competency in nursing with poorly defined roles, responsibilities and duties in this region, which can lead to an absence of the use of nurses in clinical care.

The current study has triggered the need for new policies and clearly defined roles for

nursing staff as well as the development of community health nurses and social workers alongside counselling and educational programs for children with thalassemia.

Nurses in Kurdistan have a limited role in terms of making decision and do not consider themselves to be involved in initial or ongoing patient education. However, they do have the role of explaining the risk of non-adherence to the chelation drugs for the families. They do not consider themselves to support the patient's psychological state. The knowledge of the degree educated nurses in Kurdistan regarding thalassemia is better than the knowledge of the trained nurse with experience but with no degrees in nursing. There is however an overall lack of detailed knowledge of genetics and some interventions. There is a lack of nursing documentation other than recording of abnormal events and a lack of knowledge about and engagement in continuous training about thalassemia.

Recommendations

Further studies should evaluate the role of the nurse in Kurdistan. Guidance and support for further education and training is required in order to enable nurses to fulfil their potential. Continuous education is necessary to facilitate the nurses to provide enhanced physical, psychological and genetic care. The possibilities of how these may be achieved need to be explored within the university and the hospital. Future research should consider how increased psychological support for thalassemic families can be achieved and there should be development of job descriptions for nurses at all levels.

References

1. Godino L, Turchetti, D, Skirton H. Knowledge of genetics and the role of the nurse in genetic health care: a survey of Italian nurses; *J Adv Nurs*. 2013 May; 69 (5): 1125-1135. http://dx. doi: 10.1111/j.1365-2648.2012.06103.x

2. Terreros MC, Rowold D, Mirabal S and Herrera R. Mitochondrial DNA and Y-chromosomal stratification in Iran: relationship between Iran and the Arabian Peninsula. *J Hum Genet*.2011 Mar; 56(3): 235-246. http://dx. doi: 10.1038/jhg.2010.174

3. Skirton H, O'Connor A, Humphreys A. Nurses' competence in genetics: a mixed method systematic review. *J Adv Nurs*. 2012 Nov; 68(11): 2387-98. http://dx. doi: 10.1111/j.1365-2648.2012.06034.x.

4. Clarke GM and Higgins TN. Laboratory Investigation of Hemoglobinopathies and Thalassemia. *Clin Chem*. [Internet] 2000 Aug; 46 (8Pt2): 1284-90. Available from: http://www.clinchem.org/content/46/8/1284.full

5. Giordano PC, Bouva MJ and Harteveld CA. Confidential Inquiry Estimating the Number of Patients Affected with Sickle Cell Disease and Thalassemia Major Confirms the Need for a Prevention Strategy in The Netherlands. *Hemoglobin.* [Internet] 2004; 28 (4):287-296. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15658185

6. Lee YL, Lin DT and Tsai SF. Need for systematic education for patients and caregivers to improve adherence to treatment. *J Clin Nurs*. 2009 Feb; 18 (4): 529–538. http://dx doi: 10.1111/j.1365-2702.2007.02150.x.

7. Kruijver IP, Kerkstra A, Francke AL, Bensing JM, van de Wiel HB. Evaluation of communication training programs in nursing care: a review of the literature. *Patient Educ Couns*. [Internet] 2000 Jan; 39(1):129-145. Available from: http://www.ncbi.nlm.nih.gov/pubmed/11013554

8. Aimiuwu E, Thomas A, Roheemun N, Khairallah T, Nacouzi NA, Georgiou A et al. *A Guide for the haemoglobinopathy nurse*. Thalassaemia International Federation. Teamup Creations Ltd. 2012

9. Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *J Clin Epidemiol.* [Internet] 2002 Nov; 55(11): 1130–43. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12507678

10. Larsson IE, Sahlsten MJ, Sjöström, B, Lindencrona, CS, Plos KA. Patient participation in nursing care from a patient perspective: a Grounded Theory study. *Scand J Caring Sci*. [Internet] 2007 Sep; 21(3): 313–320. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17727543

11. Gharaibeh H, Oweis A, Hamad KH. Nurses' and midwives' knowledge and perceptions of their role in genetic teaching. *Int Nurs Rev*. 2010 Dec; 57(4): 435-442. http://dx doi: 10.1111/j.1466-7657.2010.00814.x

12. Sully P and Dallas J. *Essential Communication Skills for Nursing*. Elsevier Health Sciences. 2005. P166. Available from http://books.google.iq/books?id=70WYVXHkNQ4C&printsec=frontcover&hl=ar&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false

13. Kaheni S, Yaghobian M, Sharefzadah GH, Vahidi A, Ghorbani H, Abderahemi A. Quality of Life in Children with B-Thalassemia Major at Center for Special Diseases. *Iran J Ped Hematol Oncol.* [Internet] 2013 Jul 22; 3(3): 108-113. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3921875/

14. Mok E, Chiu P C. Nurse–patient relationships in palliative care. *J Adv Nurs*. [Internet] 2004 Dec; 48(5):475–483. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15533085

15. Allahyari A, Alhany F, Kazemnejad A, Izadyar I. The effect of family-centered empowerment model on the Quality of Life of school-age B-thalassemic children. *Iran J Pediatr*. [Internet] 2006; 16(4): 455-461. Available from: http://ijp.tums.ac.ir/index.php/ijp/article/view/670

16. Abu Shosha GM. Needs and Concerns of Jordanian Mothers with Thalassemic Children. *J Am Sci*. [Internet] 2014; 10(1):11-16. Available from: http://www.jofamericanscience.org.

17. Scalone L, Mantovani LG, Krol M, Rofail D, Ravera S, Bisconte MG, et al. Costs, quality of life, treatment satisfaction and compliance in patients with β-thalassemia major undergoing iron chelation. *Curr Med Res Opin*. 2008 Jul; 4(7):1905-17. http://dx doi: 10.1185/03007990802160834

18. Cowen PS, Reed DA. Effects of Respite Care for Children with Developmental Disabilities: Evaluation of an Intervention for At Risk Families; *Public Health Nurs*. [Internet] 2002 Jul-Aug; 19(4): 272–283. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12071901

19. Yardumian A.; Telfer P.; Darbyshire, P.; Darlison M.; Kinsey S. et al. *Standards for the clinical care of children and adults with thalassemia in the UK.* 2nd ed. United Kingdom Thalassemia Society. Standards for the clinical care of children and adults with thalassemia in the UK: 2008. P 8-74

20. Krippendorf, K. *Content analysis: An introduction to its methodology*. Thousand Oaks, CA; Sage Publications. 2005. P 81-95

21. Aziz K, Sadaf B and Kanwal S. Psychosocial problems of Pakistani parents of Thalassemic children: a cross sectional study done in Bahawalpur, Pakistan. *Bio psychosoc Med*. [Internet] 2012 Aug 1st; 6(15): 6-15. http://dx doi:10.1186/1751-0759-6-1 Available from: http://www.bpsmedicine.com/content/6/1/15

22. Wahab AJ, Naznin M, Nora M Z, Suzanah A R, Zulaiha M.et al. Thalassaemia: A Study on The Perception of Patients and Family Members.. Med J *Malaysia*. [Internet] 2011Oct, 66 (4): 326-

334. Available from: http://www.ncbi.nlm.nih.gov/pubmed/22299552
23. Shabila NP, Al-Tawil NG, Tahir R, Shwani FH, Saleh AM, Al-Hadithi TS. Iraqi health system in Kurdistan region: medical professionals' perspectives on challenges and priorities for improvement. *Confl Health*. 2010 Nov 30; 4:1-19. http://dx doi:10.1186/1752-1505-4-19
24. World Health Organisation. *Iraq Briefing Northern Governorates: Human Resources and Education,* Geneva: WHO, 2000.
25. Henderson S. Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *J Clin Nurs*. [Internet] 2003 Jul; 12(4): 501-508. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12790863
26. Gharaibeh H, Amarneh BH and Zamzam SZ. The psychological burden of patients with beta thalassemia major in Syria. *J Pediatr Int.* 2009 Oct; 51(5): 630- 636. http://dx doi: 10.1111/j.1442-200X.2009.02833.x
27. Ryan AA and Scullion HF. Nursing home placement: an exploration of the experiences of family careers. *J Adv Nurs*. [Internet] 2000 Nov; 32(5): 1187-95. Available from: http://www.ncbi.nlm.nih.gov/pubmed/11115004
28. Messina G, Colombo E, Cassinerio E, Ferri F, Curti R, Altamura C et al. Psychosocial aspects and psychiatric disorders in young adult with thalassemia major. *Intern Emerg Med*. 2008 Oct; 3(4): 339-343. http://dx doi: 10.1007/s11739-008-0166-7
29. Al-Kloub M, Salameh,T, Froelicher, E. Impact of psychosocial status and disease knowledge on adherence among thalassemia major adolescents, *INT J CLIN PRACT*. 2014 Jun; 20 (3): 265-274. http://dx doi: 10.1111/ijn.12143
30. Lee Y, Lin DT and Tsai SF. Disease knowledge and treatment adherence among patients with thalassemia major and their mothers in Taiwan. *J Clin Nurs*.. 2009 Feb; 18 (4): 529–538. http://dx doi: 10.1111/j.1365 2702.2007.02150.x.
31. Cheevakasemsook A, ChapmanY, Francis K, Davies C. Nursing documentation complexities. *Int J Nurs Pract*. [Internet] 2006 Dec; 12(6): 366–374. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17176310
32. Modell B and Darr A. Genetic counselling and customary consanguineous marriage. *Nat. Rev. Genet*. 2002 Mar; 3: 225-229. Available from: http://dx doi:10.1038/nrg754
33. Terzioğlu F, Dinc L. Nurses' Views on Their Role in Genetics. *J Obstet Gynecol Neonatal Nurs*. [Internet] 2004 Nov-Dec; 33 (6): 756–764. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15561664
34. Hsiao CY, Lee SH, Chen SJ, Lin SC. Perceived knowledge and clinical comfort with genetics among Taiwanese nurses enrolled in a RN-to-BSN program. *Nurse Educ Today*. 2013 Aug; 33(8): 802- 807. http://dx doi: 10.1016/j.nedt.2012.02.020.
35. Moore MC, Anthony R, Lim YW, Jones SS, Overton A. The Future of Health Care in the Kurdistan Region- Iraq: Toward an Effective, High-Quality System with an Emphasis on Primary Care. *RAND cooperation*. 2014. P 95-119 Available from: http://www.rand.org/pubs/monographs/MG1148-1.html

Appendix 1. Questions to guide the Interview

Study dimensions	Questions
The nurse's role	**1.** What is your role as a nurse in assessing thalassemia patient?
	2. What is your role in blood transfusion?
	3. What is your role in health education of thalassemic patients?
	4. What is your role if a patient is non adherent to the treatment?
	5. Can you record your nursing note and their management in case sheet?
Knowledge	1. What are the signs of the thalassemia in a patient?
	2. What is the real problem in thalassemia?
	3. How do you know that the patient has iron overload?
	4. How a drug of chelation therapy is chosen for the patient and what is the dose?
	5. Do you give whole blood to the patients?
	6. How many types of chelation therapy drugs are available?
Knowledge deficit	1. Can you tell me which type of HbF is prevalent in thalassemic patients?
	2. What is the percentage of HbF in major thalassemic patients?
	3. Are there any prenatal tests available?
	4. What is the unit of serum ferritin?
	5. Do you have a follow –up program?