

## LEVEL OF AWARENESS REGARDING SICKLE CELL ANEMIA

**Alnasser Saad mohammed S, Yazeed Saad Alotaibi, Mazen Mohammed Alghamdi, FAHAD MUQHIM FAISAL ALAMRI, ALANAZI ABDULELAH SABR S, Abdullah Ibrahim Alharbi, Hassan Ali Assiry, Alfuraih Albara Ali, QAISI ABDULAZIZ AHMAD M, ALORAIIFI TORKI NASSER A, Aldulbah Khulud Ali M, ALGHAMDI AHMAD SALEH A, ABUOALKHER DAREEN TLAL M, Ala abdulla Almadhari, Aeshah AbdulmohsenAlotibi, Alrefeai Bassma Talal O, SALEM FAHAD ALANAZI, ALAJROUSH ABDULMALIK W**

*Corresponding Author: Alnasser Saad mohammed S Ministry of Health, Saudi Arabia*

**ABSTRACT**

**Background:** Millions of people suffer from sickle cell disease (SCD), a collection of hereditary blood diseases. This syndrome is often caused by sickle cell disease (SCD), which has a global prevalence of 112 cases per 100,000 people. Many regions, including Sub-Saharan Africa, Saudi Arabia, India, South and Central America, and the Mediterranean, have high rates of sickle cell disease (SCD). To determine the degree of public knowledge and awareness regarding sickle cell disease (SCD), we carried out a survey in Tabuk, Saudi Arabia. **Methods:** In this study, 386 residents of Tabuk who were over the age of 18 and represented both genders and different nationalities were included in the cross-sectional observational design. A standardized questionnaire that was created from earlier research was used to collect demographic information and sickle cell disease awareness.

**Results:** A total of 386 persons who met the predefined inclusion criteria and lived in Tabuk, Saudi Arabia, were included in the current study. 47.4% of the participants were between the ages of 18 and 25. With 24.1% of participants aged 18–25, 10.1% of participants aged 26–35, 7.3% and 6.55% of participants aged 36–45, and a sizable percentage of participants aged over 45, the majority of participants possessed a sufficient level of expertise. **Conclusion:** The survey participants demonstrated a satisfactory degree of understanding on the prevalence of sickle cell disease (SCD) in the Kingdom of Saudi Arabia (KSA).

**Keywords:** Sickle cell disease, Awareness, Tabuk, Saudi Arabia.

**• INTRODUCTION**

Sickle cell disease (SCD) is an inherited hematological ailment marked by several genetic blood anomalies that endure throughout a person's life and impact a significant global population (Oluwole et al., 2022). The sickle cell disease results from the replacement of valine with glutamic acid at the sixth position in the beta chain of hemoglobin (Hb). This disease is transmitted by an autosomal-recessive inheritance pattern. The synthesis of sickle hemoglobin (HbS) results from a particular point mutation, resulting in a variant of hemoglobin that demonstrates reduced solubility relative to standard fetal or adult hemoglobin (Uche et al., 2017). Sickle cell disease (SCD) has a global frequency of about 112 cases per 100,000 individuals, making it one of the most common infectious diseases worldwide (Hurissi et al., 2022). Numerous investigations have been undertaken in Saudi Arabia to ascertain the prevalence of sickle cell disease (SCD). The research done have revealed evidence of the widespread occurrence of this condition across the nation, especially in the eastern and southern regions. The

incidence of sickle cell disease (SCD) is greatest in the southern region. Alhejji et al. (2018) projected the prevalence of sudden cardiac death (SCD) to be 145 cases per 100,000 individuals in the eastern region, 24 cases per 100,000 individuals in the southern region, 12 cases per 100,000 individuals in the western region, and 6 cases per 100,000 individuals in the central region.

In 2022, a study was conducted to stimulate interest in knowledge assessment, enhance understanding of sickle cell anemia (SCA) across various sectors of Saudi society, and facilitate the dissemination of additional information regarding this medical condition. A study was done to evaluate the preparedness of individuals and communities for premarital testing as a preventive strategy against genetic illnesses. Sixty point sixteen percent of participants exhibited awareness of the existing conditions. A total of 53 individuals, or 13.3 percent of the sample, exhibited knowledge of the effects of sickness on children when both parents were affected. Khalifa et al. (2022) conducted a study with 390 participants, which demonstrated a consensus rate of 97.5% on the significance of premarital counseling.

A descriptive cross-sectional survey was conducted in 2019 to examine the population of Al- Ahsa. A total of 221 participants from Saudi Arabia actively participated in the study by willingly completing self-administered questionnaires and providing informed consent via a permission form. The findings indicate a reasonable level of knowledge regarding Sickle Cell Disease (SCD) among the general populace. It is essential to focus education and foster awareness. It is essential for the government to continue enforcing regulations and requiring premarital testing, as argued by Alhejji et al. (2018). This study aimed to evaluate the community's knowledge and awareness of sickle cell disease (SCD) among the general public in the Tabuk region of Saudi Arabia. A recent review of the literature reveals that no previous research has particularly addressed this issue in the Tabuk region.

## • METHODOLOGY

### Study design and setting

This examination is a cross-sectional observational study conducted in Tabuk city, situated in the Northwestern region of Saudi Arabia. The study was conducted from July 2021 to October 2022.

### Study population

Male and female citizens of all ethnicities in Tabuk City

#### *The Inclusion criteria of this study*

All persons, irrespective of gender or nationality, residing in Tabuk, Kingdom of Saudi Arabia, who are 18 years of age or older and identify as male or female, consent to participate in the study. **Exclusion criteria**

Individuals under 18 years of age and citizens residing beyond the geographical confines of Tabuk city who indicate their refusal to participate in the activity.

### Sample size

The Qualtrics calculator was employed to determine a sample size of 386, with a confidence level of 95%. To perform a study with a 95% confidence interval, a 5% acceptable error margin, and a design effect factor of 2, a minimum of 386 participants is necessary. To improve the accuracy of

the study, the participant count was subsequently increased by 45%. The sample size is determined using the web tool at <http://www.raosoft.com/samplesize.html>.

### **Rationale of topic selection**

Sickle cell illness is a common disorder that can be alleviated via community education. The prevalence of the sickle-cell trait in Saudi Arabia is estimated between 2% and 27%, with the highest incidence noted in the Eastern region. Furthermore, it is estimated that as many as 2.6% of individuals in the population may possess sickle-cell disease (SCD). Assessing the public's awareness of this widespread disease will aid in the execution of preventive strategies.

### **Method for data collection and instrument**

The researchers utilized a standardized questionnaire for data gathering in the study. The creation of this instrument was guided by an extensive analysis of relevant studies conducted in Saudi Arabia and elsewhere. The questionnaire consisted of 20 questions, divided into two unique portions. The initial section includes demographic characteristics, such as age, gender, educational attainment, and marital status. The second component of this study investigates the evaluation of knowledge and awareness regarding sickle cell disease (SCD), including aspects such as inheritance patterns, diagnostic techniques, and possible therapeutic interventions. The data was collected via a questionnaire distributed through a Google Form. The structured questionnaire utilized in this study was adapted from a prior research work (Khalifa et al., 2022).

### **Statistical analyses**

A survey tool consisting of 12 questions and socio-demographic factors was employed to assess the knowledge and awareness levels of the participants in the sample group. Subsequent to data extraction, a procedure of verification, coding, and input into analytical tools was executed. The software utilized in this investigation was IBM SPSS version 22, created by SPSS, Inc. in Chicago, IL. A comprehensive study was performed on all factors, including demographic characteristics and assessments of awareness and knowledge. This analysis entailed scrutinizing the frequency and percentage distribution of the variables. Eleven survey items related to awareness and knowledge were used into the study, from a total of seventeen available items. Each correct answer receives one point. Thereafter, the aggregate total of the individual scores for the various components was calculated. Incorrect responses receive a value of 0, whereas correct ones receive a value of 1. The participants' awareness and knowledge were then evaluated. Participants with scores between 0 and 3 were classified as possessing a poor level of awareness and knowledge. Individuals who attained scores ranging from 4 to 7 were categorized as possessing a moderate level of awareness and knowledge. Participants scoring 8 or higher were considered to possess a high level of awareness and expertise.

Chi-Square tests were performed to evaluate the correlation between demographic variables and participants' knowledge and awareness levels regarding sickle cell disease and its determinants. The approaches were validated using a significance threshold of  $p < 0.05$ . The study's results were conveyed through tables and graphs.

## • RESULTS

This study included 386 adult individuals from the Tabuk region of Saudi Arabia who fulfilled the established inclusion criteria. The predominant proportion of participants (47.4%) was within the age range of 18 to 25 years. Table 1 demonstrates that most participants exhibit a notable level of awareness and knowledge of sickle cell disease, including its diagnosis, symptoms, risk factors, and therapy approaches.

A considerable number of participants demonstrated a notable level of understanding on age differences. Specifically, 24.1% of individuals aged 18 to 25 and 10.1% of those aged 26 to 35 had a satisfactory degree of understanding. Moreover, 7.3% of persons aged 36 to 45 years and 6.55% of those over 45 years demonstrated a notable level of expertise. No statistically significant correlation was identified between the participants' age and their level of awareness and knowledge ( $p = .199$ ). The distribution of gender variations in degrees of awareness was determined, with 25.4% in males and 22.5% in females. Statistically significant evidence is absent to substantiate inequalities in knowledge between the genders of the participants ( $P = .317$ ). The study's findings indicate that the majority of participants were Saudi citizens, with a mere 0.3% including non-Saudis. The results pertain to the correlation between participant nationality and their levels of awareness and knowledge ( $P = .407$ ). Nonetheless, the study revealed no

statistically significant differences between the participants' nationalities and their degrees of knowledge.

The bulk of those with substantial awareness and expertise were identified as either single or married, though in differing amounts. Specifically, 23.8% of individuals were categorized as single, whilst 22.8% were classified as married, concerning their socioeconomic status. Nonetheless, save from a minor percentage of widows and divorcees ( $p = .181$ ), no statistically significant variations are observed between the participants' social position and their level of awareness and knowledge.

The data reveal a strong association between participants' educational levels and their awareness and knowledge, indicating that these levels are generally high across diverse educational backgrounds, regardless of the participants' varying educational attainment. The user's writing will be revised to conform to academic standards without incorporating any supplementary information. Eight percent of individuals identified as illiterate and five percent of those in middle school. 9.3% of high school students, 34.5% of university students, and an additional 2.8% of post-graduate students comprise the student population. The individuals exhibit no statistically significant variation in educational background and knowledge level ( $P = .188$ ). An analysis of the results concerning persons acquainted with someone suffering from sickle cell disease revealed a notable association between this familiarity and their knowledge and awareness levels. Individuals having personal links to those affected by sickle cell disease exhibited a greater level of knowledge and awareness than those without such connections. A substantial statistical difference was noted between the participants' knowledge and awareness levels and their personal connections to individuals with sickle cell disease ( $P = .000^*$ ).

**Table 1** Selected characteristic of the sample and the association with the awareness and knowledge level regarding sickle cell anemia and its factors, in Tabuk region

				Awareness and Knowledge Level			
Characteristics of the sample		N=386	%	Good	Intermediate	Poor	P
Age in year	From 18 to 25	183	47.4	93(24.1)	68(17.6)	22(5.7)	.199
	From 26 to 35	77	19.9	39(10.1)	32(8.3)	6(1.6)	
	From 36 to 45	71	18.4	28(7.3)	39(10.1)	4(1)	
	More than 45	55	14.2	25(6.5)	26(6.7)	4(1)	
Gender	Female	172	44	87(22.5)	73(18.9)	12(3.1)	.317
	Male	214	55.4	98(25.4)	92(23.8)	24(6.2)	
Nationality	Saudi	381	98	184(47.7)	162(42)	35(9.1)	.407
	Non-Saudi	5	71.3	1(.3)	3(.8)	1(.3)	
Marital status	Single	198	51	92(23.8)	82(21.2)	24(6.2)	.181
	Married	177	45.9	88(22.8)	78(20.2)	11(2.8)	
	Divorced	8	2.1	3(.8)	5(1.3)	0(0)	
	Widow	3	.8	2(.5)	0(0)	1(.3)	
Education	Illiterate	5	1.3	3(.8)	1(.3)	1(.3)	.188
	Primary school	0	0	0(0)	0(0)	0(0)	
	Middle school	2	.5	2(.5)	0(0)	0(0)	
	Secondary school	66	17.1	36(9.3)	21(5.4)	9(2.3)	
	University	281	72.8	133(34.5)	124(32.1)	24(6.2)	
	Post-graduate	32	8.3	11(2.8)	19(4.9)	2(.5)	
Knowing someone who has sickle cell disease?	Yes, I know	174	45.1	124(32.1)	50(13)	0(0)	.000*
	I do not know	212	54.9	61(15.8)	115(29.8)	36(9.3)	

\*Significant

**Figure 1** Shows that most of the participants have a good level of awareness and knowledge of sickle cell disease, its diagnosis, symptoms, risk factors and its management

**Table 2** Shows the questions by which participants' level of awareness and knowledge about sickle cell disease and its factors was measured. The results are detailed below:

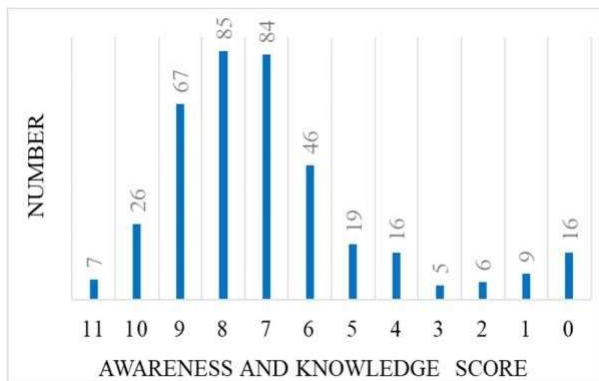
Awareness and knowledge about (sickle cell disease)		N	%
Have you ever heard of sickle cell disease (SCD)?	Yes	340	87.6
	Bone disease	8	2.1
	Gastrointestinal disease	3	.8
	Blood disease (correct)	337	86.9

LEVEL OF AWARENESS REGARDING SICKLE CELL ANEMIA

What kind of diseases are SCD classified?	answer)		
	Lymphatic disease	0	0
	Nerve disease	1	.3
	I don't know	37	9.5
Do you know someone who has SCD?	Yes	174	44.8
If yes? How do you know them?	Mother/Father	7	1.8
	Brother/Sister	29	7.5
	Aunt/Uncle	10	2.6
	Cousin	1	.3
	Friend	100	25.8
	Other	35	9.0
Awareness and Knowledge about (SCD) Risk factors		N	%
How do you think people with SCD get affected?	Malnutrition	20	5.2
	By virus	3	.8
	By bacteria	3	.8
	Inherited (correct answer)	301	77.6
	Mineral deficiency	12	3.1
	Malnutrition	20	5.2
	I don't know	47	12.1
Awareness and Knowledge about (SCD) Clinical features		N	%
What are the symptoms of sickle cell anemia?	Pale skin (correct answer)	10	2.6
	Fatigue and tiredness (correct answer)	39	10.6
	A headache	9	2.6
	Chronic pain episodes (correct answer)	28	7.6
	Diarrhea	5	1.5
	Vision problems (correct answer)	7	2.0
	Recurring infection (correct answer)	16	4.3
	Vomiting	4	1.2
	I don't know	66	17.0
What do you think about the severity of SCD?	Very serious (correct answer)	179	46.1
	Moderate	100	25.8
	Not serious	18	4.6
	I do not know	89	22.9
Awareness and Knowledge about (SCD) diagnosis		N	%
	Ultrasound	2	.5

Which one of those is the test to diagnose SCD?	Blood test (correct answer)	332	85.6
	Urine / feces test	4	1.0
	I do not know	48	12.4
What is the probability for achild to get SCD? If both parents had SC	All children	68	17.5
	50% of offspring	130	33.5
trait?	25% of offspring (correct answer)	73	18.8
	I do not know	115	29.6
Do you think pre-marital examinationis necessary?	Yes (correct answer)	348	90.2
	No	1	.2
	I do not know	37	9.6
	Separate	100	25.9
	Continue their marriage	6	1.6

f a married couple foundout that their genetic test showed the chance of having a child with SCD,what do you think they should do?	Consult a doctor (correct answer)	241	62.4
	I do not know	39	10.1
Awareness and Knowledge about (SCD) management		N	%
Is SCD curable?	Yes	85	22
	No (correct answer)	138	35.8
	I do not know	163	42.2



**Figure 2** Distribution of awareness and knowledge score about sickle cell anemia among the studied population, in Tabuk Region

## • DISCUSSION

The discovery of genes impacted by the disease in sickle transgenic mice and humans is being enhanced through the use of expression microarrays across several organs. Following the identification of these genes, one might investigate polymorphisms to discern genetic modifiers that influence individual risk assessment. This knowledge can enable the formulation of sensible therapies prior to the onset of organ damage.

Sickle Cell Disease (SCD) is a matter of considerable public health concern. It is essential to have a comprehensive grasp of SCD and its related consequences to manage this condition successfully. A recent survey of scholarly literature indicates a deficiency of research on the evaluation of the Specific Carbohydrate Diet (SCD) in Tabuk, Saudi Arabia. Therefore, it is essential to evaluate the perception of the Saudi Arabian populace on the Saudi Commission for Tourism and National Heritage (SCTH). Prior community-based surveys in major urban centers revealed that African Americans possess minimal awareness about sickle cell disease (SCD), which contrasts recent research findings that indicate a significant enhancement in their

comprehension (Vassiliou et al., 2001). Adewoyin et al. (year) exhibited significant expertise in public health concerning sickle cell disease (SCD) in Nigeria.

The population of Bahrain in the Middle East demonstrates a notable level of awareness and understanding of sickle cell disease (SCD). The preventive measures executed in Bahrain were well-received and consistent with contemporary study findings. Panter-Brick (1991) noted that the public of Bahrain in the Middle East exhibited a thorough understanding of sickle cell disease (SCD), and the preventive measures enacted in the country were broadly recognized and appreciated. Alfahl et al. (2022) indicated that a prior study found 98 percent of participants were knowledgeable with Sudden Cardiac Arrest (SCA); however, in our investigation, only 88 percent of persons exhibited awareness of SCA.

Regarding the classification of sickle cell disease (SCD), it was determined that 98% (n=2836) of the participants were aware that SCD is a hematological illness. In contrast, a little segment of participants, accounting for 2% (n=59), were unaware of the characteristics of SCD, while an even lesser fraction, representing 0.2% (n=6), erroneously saw it as an infectious disease. Furthermore, 0.1% (n=3) of the remaining individuals mistakenly perceived SCD as a cardiovascular condition. A substantial majority of participants (87%) recognized sickle cell disease (SCD) as a hematological disorder. A minority of the remaining participants (9%) indicated ambiguity about their knowledge of SCD, while a tiny percentage (2%) erroneously considered it to be a disorder affecting the skeletal system. A previous study by Alfahl et al. (2022) shown that 98% of participants recognized the illness under inquiry as a hematological issue. The other 2% of participants either exhibited confusion regarding their understanding or had misconceptions about the condition. Specifically, 0.2% of participants perceived it as an infectious disease, whereas 0.1% erroneously classified it as a cardiovascular ailment. The participants were queried on their knowledge and comprehension of the risk factors linked to Sickle Cell Disease (SCD). Seventy-seven percent of responders accurately recognized SCD as a genetic condition. A lesser percentage (12%) expressed uncertainty, although a minority posited that malnutrition (5%) or mineral insufficiency (3%) could contribute to the onset of SCD. The enhancement of community awareness and the incorporation of comprehensive information in school curricula concerning this issue can be credited to the initiatives of the Saudi Ministry of

Health (Panter-Brick, 1991). This study investigates the awareness of sickle cell disease among the

general community in Al-Ahsa, Saudi Arabia.

A significant proportion of the study population (46%) expressed agreement regarding the profound impact of sickle cell disease (SCD) on health status and clinical manifestations, in contrast to a minority (22%) who lacked awareness on this matter. This finding suggests that the majority of participants possessed knowledge regarding the influence of SCD on overall well-being and cognitive functioning. A recent poll revealed that 60.0% of persons diagnosed with sickle cell disease (SCD) in Saudi Arabia believe this condition adversely affects their academic performance. Furthermore, according to Kanter and Kruse-Jarres (2013), a study conducted on Saudi Sickle cell patients revealed that 37.5% of them received support from specialized after-school activities. Furthermore, a notable association exists between marital status and the awareness of the impact of sickle cell disease (SCD) on academic achievement. This discovery corresponds with our research, which indicated that 18.8% of participants were aware of the 25% probability of offspring acquiring sickle cell disease when both parents possess the sickle cell trait. Approximately 99% of the public believes that premarital examination is a vital practice. This observation may be attributed to the increased attentiveness of parents of children with sickle cell disease (SCD) regarding their overall well-being (Memish et al., 2011). A significant majority of participants (85%) accurately identified that the diagnosis of sickle cell disease (SCD) is established using a blood test. This reaction is consistent with current literature, since a blood test can identify the precise kind of hemoglobin linked to sickle cell anemia (Onimoe & Rotz, 2020).

The participants were also asked about their thoughts of the medicinal curability of SCD. Of the respondents, 35% expressed a negative viewpoint, 22% held an affirmative stance, and 42% indicated uncertainty on the matter. In a comparison analysis, Alfahl et al. (2022) discovered that a predominant majority of participants (87%) held the conviction that the disease under examination was incurable. Conversely, a small percentage (2%) indicated that it was indeed curable, while 11% reported uncertainty regarding its curability.

## Limitations

A main limitation of this study was the absence of validation of the questionnaire before its deployment. The study's internal consistency, reflected by a coefficient of 0.739, was deemed weak. A further limitation of the study was the omission of an analysis of the most successful ways for enhancing knowledge among the population on the significant complications of sickle cell disease, including renal failure, stroke, and hospitalization.

## • CONCLUSIONS

The study contributors shown a satisfactory level of comprehension on the prevalence of sickle cell disease (SCD) in Tabuk. The individuals were aware that Saudi Arabia is among the countries with the highest prevalence of sickle cell disease (SCD) worldwide. Moreover, a significant level of comprehension was noted about illness classification, diagnostic procedures, and most survey participants exhibited awareness of the clinical features related to Sickle Cell illness (SCD). Nonetheless, there seemed to be an insufficient comprehension of disease transmission patterns, along with a restricted awareness among participants regarding the probability of a child inheriting sickle cell disease (SCD) when both parents possess the sickle cell (SC) trait. Furthermore, most participants had a deficiency in

knowledge in these domains.

### REFERENCES AND NOTES

1. Alfahl SO, Alhakeem MH, Almshhen SR, Sheikh ZB, Alqelaiti AW, Abdulmaqsud MA, Alhawsah SA. Awareness of the Saudi population in Medinah about the complications of sickle cell disease. *Int J Med Dev Ctries* 2022; 6(3):428-440.
2. Alhejji AE, Al-Ali G, Alshareet M, Alsultan MA, Wabar MA, Alshareet A, Alshareet A. Awareness about sickle cell disease among general population in Al-Ahsa, Saudi Arabia. *Int J SciEng Res* 2018; 9(10).
3. Hurissi E, Hakami A, Homadi. Awareness and acceptance of hematopoietic stem cell transplantation for sickle cell disease in Jazan Province, Saudi Arabia. *Cureus* 2022. doi: 10.7759/cureus.21013
4. Kanter J, Kruse-Jarres R. Management of sickle cell disease from childhood through adulthood. *Blood Rev* 2013; 27:279–287.
5. Khalifa AM, Alhejaili MF, Aledaili AH. Knowledge and awareness of sickle cell anemia: Cross-sectional study among the General Population in Saudi Arabia. *Pak Bio Med J* 2022; 69–74.
6. Memish ZA, Owaidah TM, Saeedi MY. Marked regional variations in the prevalence of sickle cell disease and  $\beta$ thalassemia in Saudi Arabia: Findings from the premarital screening and genetic counseling program. *J Epidemiol Glob Health* 2011; 1:61–68.
7. Oluwole EO, Okoye CD, Ogunyemi AO. Knowledge, attitude and premarital screening practices for sickle cell disease among young unmarried adults in an urban community in Lagos, Nigeria. *Pan Afr Med J* 2022; 42.
8. Onimoe G, Rotz S. Sickle cell disease: A primary care update. *Cleve Clin J Med* 2020; 87:19–27.
9. Panter-Brick C. Parental responses to consanguinity and genetic disease in Saudi Arabia. *Soc Sci Med* 1991; 33:1295–1302.
10. Uche E, Olowoselu O, Augustine B. An assessment of knowledge, awareness and attitude of undergraduates toward sickle cell disease in Lagos, Nigeria. *Niger Med J* 2017; 58:167.
11. Vassiliou G, Amrolia P, Roberts IAG. Allogeneic transplantation for haemoglobinopathies. *Best Pract Res Clin Haematol* 2001; 14:807–822.