Haemoglobinopathies – Advancing Client Centred Care 6KNIN313

Level: 6
Credits: 15

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This handbook must be read in conjunction with module information provided on KEATS, the King’s E-Learning And Teaching Service. You will be given access to KEATS on enrolment. Important information relating to assessment and related regulations can be found in the Undergraduate Programme Handbook, available on KEATS and via the Student Services Centre.

This handbook can also be provided in alternative formats (such as large print) upon request to asc@kcl.ac.uk.
Module overview
This is a freestanding module.

Module aim
This course aims to integrate and apply knowledge of theoretical frameworks from a variety of disciplines these include biological and social sciences, nursing/midwifery and health sciences to care for individuals, families and communities with or at risk of haemoglobinopathies.

Finally, it is expected that the course will develop a practitioner capable of empowering clients through education, counselling and screening to make informed health and social choices. As well as one who is able to reflect on practice and factors that influence professional judgement, and subsequent action.

Learning outcomes
The practitioner will be able to:

1. Demonstrate and in depth knowledge and understanding of the aetiology, epidemiology and natural history of abnormal haemoglobins.

2. Categorise populations 'at risk', modes of inheritance and potential health implications. Thereby, signposting and supporting patients (and families/carers) in their understanding of their genetic condition

3. Examine and determine the sociological and psychological and biological determinants of health and illness as experienced by the client/patient. Provides empathy and understanding and works with the patient (and their family/carers) as an expert in their own condition

4. Translate relevant health and social policies, examine political philosophies and identify their impact on health and social care service provisions. Thereby working alongside and with the patient (and families/carers) to address the psychological and social impact of their condition

5. Interpret the heath care needs of patients receiving specialist haemoglobinopathy treatment; including the use of early warning tools/approaches (for example, red alert. PEWT) to identify the patient’s changing and deteriorating condition, and takes appropriate action

6. Critically apply the theoretical knowledge of developmentally, ethnically and culturally competent care in order to work collaboratively with clients and their families

7. Appraise their role in promoting health of clients/patients with or at risk of a haemoglobinopathies e.g. working with the patient (and family/carers) to manage their pain (patients with sickle cell disease)

8. Identify and facilitate ways of increasing the child, adult and their carers’ participation in their care and service developments. Developing and evaluating a self-management plan with the patient

9. Evaluate their perception of their role, re-examine their professional practices and competencies in relation to the client group; in order to actively improves and promotes services across the care pathway

10. Review and discuss current research findings and their potential application and utilisation in practice.

11. Collaborate and contribute as part of a multidisciplinary team. This includes undertaking assessment and follow up with appropriate action, including referral to medical specialists for relevant chronic health care conditions
**Teaching arrangements**

The course spans over six weeks, the first of which will be directed learning. Attendance is required on the Fridays indicated on the timetable. Please refer to the programme handbook for the attendance policy. Some sessions are designated for directed reading or other work and attendance in class is not required.

To facilitate your learning there are a number of learning strategies:

- Lectures
- Small group work
- Workshops
- Directed reading
- E-Learning
Submitting coursework
Submission your assignment is electronically through TurnItIn online via KEATS. (please see guidance below)

For this module you are assessed by Joan Walters and Jacquie Collin.

Assessment criteria
Assessment is either a Service Review or a Patient Portfolio of up to 3,000 words

Title: Service review

- Review a service provision available to a specific client group.
- Give a written account of your findings and put forward feasible proposals for its further development or improvement, using literature findings discuss the rationale for your proposals.

OR

Title: Patient Portfolio

- You are required to complete a written assignment consisting of an entry of one patient/client that you have cared for.
- In addressing the care and management of this client/patient you will focus in detail on two or three aspects of nursing care.

Formative assessment
A draft outline of up to 500 words can be submitted up to Tuesday 9 May 2017. Although there will be group tutorials, students can contact Joan Walters for individual tutorial support. The last date for this is also Tuesday 9 May 2017.
Summative assessment

Service review

Guidelines:
The assessment must demonstrate an exploration of key concepts derived from all theoretical aspects of the course, these should be integrated in the work submitted.

Consider using a variety of sources and modes for obtaining information, for example, interviewing specialists in the field or researchers, visiting voluntary organisations, talking to lay public. Seek further guidance from your course leader.

In this review it is suggested that you focus on one aspect or client group, for example, pre-conceptual health promotion and/or screening, ante-natal screening, management of client with disease in acute or community settings (chelation therapy, pain management, stroke management), neonatal screening, neonatal care services, screening of ‘at risk’ population.

Include:
- Terms of reference and scope of study
- A brief overview of aetiology, epidemiology, genetic and pathophysiological implication of the condition selected.
- DIAGRAMS MAY BE USED
- Identify how this study will contribute to improving standards of care
- Highlight relevance to professional practice - responsibility, accountability, ethics and other professional issues
- Highlight the size of the problem in the geographical area selected for study. Statistics from government/district health reports may be used as evidence.
- An overview of services available in your area or area selected for review. Does it meet the needs of the population?
- Are there any guidelines and protocols for delivery of the service? Using literature findings critically analyse these documents.
- Discuss health and social policies which influence service provision,
- What are the implications to the ‘at risk’ population?
- Proposals for improving or further developing services should be feasible and must demonstrate some understanding of the issues involved in providing such a service - consider resource implications, client autonomy and empowerment, cultural / religious aspects, race, gender and equity.

OR

Patient Portfolio

Guidelines:
It is suggested that the entries contain the following information:

The selection of a patient/client
When drawing upon clinical experiences ensure that confidentiality and anonymity are maintained and ensure that you have gained permission to include the patient/client/carer in your essay

Identify an aspect of care to be the focus of your entries. Part A (Approx. 500 words)
- Make a separate entry for your patient/client identifying and briefly describing the episodes of client care giving the rationale choosing the episodes of care. This will include an introduction of the child and their family and the underlying health disorder, the nursing problems identified and the nursing context e.g. a surgical ward or community.
Part B (Approx. 2,500 words)

- From this entry identify and discuss aspects of care management.*
- Focusing on two or three particular aspects that relate to your chosen clients will enable you to gain greater depth.
- Discuss the care delivered in relation to national and local policies, standards and guidance e.g. NICE, NSFs or professional bodies.
- Ensure that the integration of nursing with other professional roles is prominent within the essay.
- Use relevant literature to develop and support your discussion. Your assignment should be accurately referenced and include a reference list in accordance with college guidelines.
- Please note that the purpose of the portfolio is to analyse care provision and that work that consists predominately of descriptors of care will result in a fail grade.
- You are required to make explicit links between the theoretical content of this course and use specific examples of practice drawn from the chosen episodes of care.

In the conclusion
A summary of the key points from your discussion and an outline of any recommendations you have for how care could be developed or improved and; a reflection on your learning based on this experience and the areas for future personal development.

Examples of areas of focus
Organisation of discharge planning, palliative care, preparation for a procedure, a health promotion intervention, safeguarding, pain management, fluid management, blood transfusion, infection control, management of sickle lung, Priapism, psychological wellbeing, transfusion CARE

DELIVERY: Analysis of an aspect of care e.g. a counselling session, a painful episode, a delivery, administration of blood products, management of iron overload (this can be an individual client or a patient group) up to 2,500 words

Coursework submission are provided on the modules KEATS site. It is essential that you use your candidate number on all assignments/examinations. Your candidate number, which will begin with X for the academic year 2016/17, will be available via Student Records on the King’s Intranet approximately one month after you enrol.

If you are unable to submit your work by the deadline, please refer to the information in your programme handbook on “mitigating circumstances”. If you require further support in these circumstances, you are advised to contact KCLSU.

Submission date for coursework: 16 May 2017

Late submissions will be accepted for 24 hours following the submission date. All work submitted late will be marked as normal but will be capped at the pass mark for the module. If your assignment is a hard copy please ensure you date stamp it and submit it to the submission room G15 James Clerk Maxwell Building. If your assignment is submitted electronically through TurnItIn, information about how to submit late will be provided on KEATS module sites under assessment information. Please label the file with your candidate number and double-check you have submitted the correct file.

The external examiner for this module is Brian Nyatanga. Students are not to make direct contact with external examiners, in particular regarding their individual performance in assessments.
The College and its Examination Boards in the ten Faculties (Institutes/Schools, King’s Learning Institute and the Association of King’s College (AKC), work with over 500 external examiners to ensure the quality and standard of our taught awards. Find the latest report on the External Examiners Report page, navigate to the Faculty of Nursing and Midwifery section.

**Results and resubmissions for coursework**
Students will receive a provisional (unratified) mark for their coursework 4 weeks following submission. According to the method of submission as detailed on your KEATS site, if your work was submitted online you will be able to download marked coursework from KEATS; alternatively, if you completed a hard copy submission you can collect your coursework and feedback from the Student Services Centre.

To collect a hard copy assignment, you must provide your candidate number. Alternatively, you may send a stamped addressed envelope to the Student Services Centre ensuring that this is large enough to accommodate your assignments and that you have applied sufficient postage. Hard copy assignments will be retained for four weeks; if you have not collected your assignment by then, it will be destroyed.

Feedback will include the award of a numerical grade which remains provisional until ratified by the examination boards. The dates for the examination boards are available on KEATS. Ratified marks can be viewed via Student Records on the King’s Intranet, the Monday following the relevant examination board.

The marking criteria by which your work is judged are provided in full in your programme handbook. Please also refer to the section in your programme handbook on plagiarism and how to avoid it. If you have a query about how to refer to a specific piece of work please ask your module leader, your group leader or a member of library staff for guidance or please use King’s Libguides site.

The feedback you receive on your assignment will guide you towards how to do better next time or how to maintain your existing high standard!

If you do not understand your mark or the feedback you receive please contact Joan Walters.

If you are unsuccessful, it is recommended that you contact the module leader before submitting your second attempt. This will enable the module leader to provide you with an appropriate level of support as you prepare to resubmit your work.
Learning resources

Session 1 – Structure & Function of the Red Blood Cell

PLEASE SEE ON LINE E-LEARNING, NO CLASSROOM SESSION

Learning outcomes

- Describe the structure and function of the red blood.
- Identify common abnormalities of the red blood cell and state the possible consequences of these.

Indicative reading

Please access MYREADINGLISTS - https://kcl.rl.talis.com/modules/5knino19.html

Session 2 – Genetic Inheritance

PLEASE SEE ON LINE E-LEARNING, NO CLASSROOM SESSION

Learning outcome

- Determine the patterns of genetic inheritance

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies) https://kcl.rl.talis.com/modules/5knino19.html

Session 3 – Course Introduction

Learning outcomes

- Identify learning opportunities and the assessment strategy on the course.
- Pre course quiz

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies) https://kcl.rl.talis.com/modules/5knino19.html
**Session 3 – Sickle Cell Disease and other Haemoglobin Variants Manifestation and Effect on the Individual**

**Learning outcomes**
- Demonstrate an in depth understanding of the epidemiology and demography, biology, pathophysiology clinical manifestation of the sickling disorders
- Appraise and assess the implications of sickle cell and other haemoglobin variants to childbearing woman and her unborn child.

**Indicative reading**
Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

**Session 4 – Sickle Cell Disease Clinical Management & Nursing Care**

**Learning outcomes**
- Assess and evaluate multidisciplinary approaches to the management of sickle cell disorders.
- Compare and contrast methods for effective relief of sickle cell crisis pain.

**Indicative reading**
Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

**Session 5 – Glucose-6: Phosphate Dehydrogenase Deficiency (G6PDD)**

**Learning outcomes**
- Demonstrate an understanding of the biology, pathophysiology clinical manifestation of the G6PD deficiency
- Assess and evaluate multidisciplinary approaches to the management G6PDD

**Indicative reading**
Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html
Session 6 – The Thalassaemias and other Haemoglobin Variants Manifestation and Effect on the Individual

Learning outcomes

- Demonstrate an in depth understanding of the biology, pathophysiology clinical manifestation of thalassaemia and other haemoglobin variants
- Appraise and assess the implications of thalassaemia and other haemoglobin variants to childbearing woman and her unborn child.

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

Session 7 – Thalassaemia: Clinical Management and Nursing Care

Learning outcomes

- Assessment and evaluation of multidisciplinary approaches to the management of the thalassaemia and other haemoglobin variants.
- Critical examination of the care needs of patients receiving specialist haemoglobinopathy treatment.
- Care needs of the patient receiving life-long blood transfusion therapy
- Outline advances in treatment - bone marrow transplantation, gene therapy, herbal remedies and bio-chemical advances

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

Session 8 – Complex Pain Management

Learning outcomes

- Compare and contrast methods for effective relief of sickle cell crisis pain.
- Critically examine potential impact of chronic pain, its long-term effect on the individuals and their family, and the nursing care needs of patients experiencing acute or chronic pain.

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html
Session 9 – Laboratory Investigations

Learning outcomes

• Identify test available to detect carrier and disease state
• State the distribution of values in the target population
• Discuss policy on further investigations

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

Session 10 — Genetic Screening and the Counselling

Learning outcomes

• Categorise populations “at risk”, modes of inheritance and potential health implications,
• Discuss how the disease affects social, cultural and psychological functioning and critically examine implications for health care delivery practice.

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

Session 11 – Transition

Learning outcomes

• Describe the key component of adolescent development
• Outline why a transition process for paediatric services to adult services are necessary
• Describe what makes an adolescent/young person friendly environment
• Critically appraise transition models

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies) -
https://kcl.rl.talis.com/modules/5knino19.html
Session 12 – The Hospital Community Interface

Learning outcomes

- Demonstrate an understanding of the community services available to clients living with a haemoglobinopathy
- Evaluate the roles and responsibilities of practitioners working with clients in the community
- The place of case management in the care of people with long term or complex health needs
- Role of self-help groups and voluntary organisations

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

Session 13 – Psychological Implications of Living with a Haemoglobinopathies

Learning outcomes

- Analyse and debate sociological and psychological factors, which contribute to clients’ experience of living with a painful conditions and identify how this influences provision of nursing services.
- Outline treatments and services which might be appropriate in maintaining client patient well-being

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html

Session 14 – The Role of the Specialist Practitioner

Learning outcomes

- Outline the Specialist Nurse and Practitioner Competences
- Outline the extended role of the practitioner and professional regulation
- Outline the role of the practitioner as client advocate
- Discuss the practitioner as a change agent in the context of specialist needs of client group in a variety of settings

Indicative reading

Please access MYREADINGLISTS (Haemoglobinopathies)
https://kcl.rl.talis.com/modules/5knino19.html
Journals
American Journal of Hematology
Blood
Blood Reviews
British Journal of Health Psychology
British Journal of Haematology
British Journal of Obstetrics & Gynaecology
Community Genetics
European Journal of Haematology
European Journal of Obstetrics & genetics
Genetics in Medicine
Gynaecology
Haematology
Hereditary
Journal of Human Genetics
Journal of Human Genetics
Human Genetics
Human Reproduction
International of Human genetics
Midwives
Prenatal Diagnosis
Professional Care of Mother and Child
Sociology of health and Illness
Social Science & Medicine
Transfusion

Databases
The Cochrane Database of Systematic Reviews
Module evaluation
At the end of the module you are requested to complete the short online evaluation which will be available on your module KEATS site. Student evaluations are very important to us and are required by Health Education England and the regional London Local Education and Training Boards.

Action from previous evaluations
The only request was for this course to be twice as long as it is currently set up which is not possible under the existing programme.

Action: Resources for self-directed learning have been increased on the e-learning site (KEATS) for 2016-17.
<table>
<thead>
<tr>
<th>Teaching mode</th>
<th>Date</th>
<th>Type of Session</th>
<th>Title</th>
<th>Time</th>
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<td>Sickle Cell Disease: Pathophysiology &amp; clinical manifestation</td>
<td>10.30-13.00</td>
<td>Joan Walters</td>
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<td>Seminar</td>
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<td>Seminar</td>
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<td>Psychological Impact of living with an haemoglobinopathy</td>
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**Location key:**

WEC – Weston Education Centre, Denmark Hill Campus (CR2 = Classroom 2; BWS = Bill Whimster Suite)

NHH – New Hunts House, Guy’s Campus

WW – West Wing, Guy’s Campus