Aiming for a seamless service for the baby with jaundice
Stephanie Michaelides

Introduction

Jaundice in the newborn is a common condition, hence often detected by midwives. Physiological jaundice is estimated as affecting around 60–70% of babies, while pathological jaundice is less common (National Institute for Health and Care Excellence (NICE) 2016). However, although pathological jaundice is less common the effects can be significant and sometimes catastrophic. Jaundice may result in long-term morbidity including kernicterus, which is considered by some to be largely preventable and has been suggested as a ‘never event’ in the NHS (Ives 2011). Midwives, and others providing maternity and newborn care, must be vigilant and aware of the causes, effects and management of jaundice. Practitioners need to ensure that mothers and families are well informed to reduce the likelihood of problems...
occurring and to protect babies from harm. There is a complex balance between seeing maternity care as a normal transition to motherhood and being acutely aware of potential problems and deviations from the norm. This is enhanced by a more individualised and personalised approach to care (NHS England 2016). In this article, the issue of neonatal jaundice and the care that may be required is explored, using two case studies, and suggests the use of a care plan on which to base provision of care. This is set out within the context of the Atain project which provides an important opportunity to focus on, examine and improve care, providing tools and resources for service providers, and women and families of newborns.

Most mothers and babies remain healthy throughout the process of labour and birth. Many are transferred to the care of the community team after six hours and others within one or two days following birth. However, in recent years, the pressure on services has impacted on midwifery care in the community — this might mean that in some areas the mother no longer receives regular postnatal home visits from a midwife. Instead she may only have telephone contact with the midwife, be asked to attend a postnatal clinic with her baby, or be visited by a maternity support worker who then reports back to the midwife (Lewis 2009, RCM 2014). This is not necessarily what most women would choose, and some research suggests that in terms of infant health and improved maternal satisfaction, there are still benefits from home visiting (Yonemoto et al 2013).

Identification of risk factors (Ives 2011) is critical in enabling the practitioner, who is transferring the baby to the community, to provide a dynamic care plan to support seamless care between hospital and community practitioners. The formation of the care plan should involve the participation of parents who are the partners-in-care with the midwife.

The midwife should firstly assess the parents’ own knowledge of newborn care, then explain the importance of continuously monitoring their baby’s well-being with regard to feeding and whether the baby is showing signs of jaundice eg yellow sclera, skin, and/or gums.

There are several steps in the process of identifying risk. These include the booking visit, antenatal results and care, labour and birth and the postnatal and neonatal period (Box 1). There are several points at which the midwife and/or care team can identify and intervene to ensure that the baby is well monitored and where morbidity and complications can be minimised. Early recognition of jaundice will identify the baby with pathological jaundice leading to early readmission to hospital. Diagnosis and treatment of hyperbilirubinaemia can begin immediately and minimise the adverse effect of toxicity to the neurological system, supporting the well-being of the newborn and parental satisfaction.

### Box 1. Babies at risk from jaundice

**Maternal**
- Ethnicity – Mediterranean and African and Asian babies
- Non-English speaking – lack of information
- Blood type ABO
- Rh incompatibility
- Drugs: diazepam (Valium), oxytocin (Pitocin)

**Neonatal factors**
- Birth trauma: cephalo-haematoma/bruising
- Poor feeding and excessive weight loss
- Infections
- Male gender
- Polycythaemia
- Gestation age less than 38 weeks
- Previous sibling with hyperbilirubinaemia.

Failure to identify the at-risk newborn will reduce the effectiveness of individualised care given to the baby and family and may certainly open the holes of the ‘swiss cheese’ of system failure first mentioned by Reason (Department of Health (DH) 2000).

The case study below, which is based on a real situation, illustrates what can happen when the ‘Swiss cheese holes’ line up. This leads to more interventions, admission to hospital, and potential risks of morbidity for the baby. One of the most common reasons for readmission is neonatal jaundice, and it has been suggested that an audit of community midwifery services may assist in addressing knowledge about jaundice and feeding issues (Roth et al 2010).
Case study 1

Monday – Mrs AS, aged 22 years, and her son Rachit had an uneventful spontaneous vaginal birth at 39 weeks’ gestation. This was Advika’s second baby – she had given birth to Sari, her first child, who had breastfed for six months and progressed well and is now a lively two-year-old and pleased to have a baby brother.

Tuesday – 26 hours after birth – Advika thought her baby Rachit was slightly jaundiced and she pointed this out to her midwife. The postnatal ward was very busy. The midwife looked at Rachit and agreed that he was slightly jaundiced and referred the baby to the junior neonatologist. After examination, the senior house officer stated that the baby was only slightly jaundiced and as the mother had been breastfeeding well and the baby was alert they could be transferred home as it should not be a problem.

No clinical screening using a bilirubinometer or blood tests for serum bilirubin were taken by the midwife or neonatal senior house officer and no instructions were given to the mother with regard to what to observe in her baby and when and who to call back if the jaundice progressed, or if the baby became sleepy and reluctant to feed.

Wednesday – Advika was visited by the team maternity support worker, who recorded that all was well with Advika, she was feeding Rachit well, and Rachit looked a little jaundiced but did not seem very sleepy.

Thursday – Day 3 (morning) – Advika was visited by the midwife, who recognised the baby as being jaundiced and informed the mother who was concerned. At this point Rachit was a little sleepy, but according to the mother feeding fairly well. The midwife recommended that Advika wake Rachit every three hours for a feed, and suggested that Advika put the baby by the sunlight, whilst maintaining his warmth. The midwife agreed that she could visit the following day if Advika was still worried.

Thursday – Day 3 (evening – 6pm) – Baby Rachit became progressively lethargic later that evening and refused to feed. Both Advika and her husband became very concerned and took the baby to the local Accident and Emergency Unit (A&E).

Thursday – 7pm – On admission to A&E, Rachit appeared very unwell. A serum bilirubin of 655 micromols/l was recorded.

Thursday – 8pm – Rachit had a seizure and was urgently admitted to the neonatal unit.

An exchange transfusion was undertaken. Later a diagnosis of kernicterus was made.

Later – Rachit has now been diagnosed as having severe cerebral palsy. Apart from being anxious for the future, and whether Rachit may recover, the parents are both angry that this had happened to their child, and do not understand what happened or why.

At a later perinatal meeting it was established that the cause of the baby’s jaundice was G6PD deficiency, a differential diagnosis that had not been considered, as although in Advika’s notes her blood group was clearly recorded, her husband’s ethnic group was not clear.

So what could be done differently…?

Reviewing case study 1, the main issues appeared to be that the baby was jaundiced due to blood type ABO incompatibility and G6PD deficiency. In analysing what went wrong, there were several critical points at which, by asking the right question, and referring to the mother’s notes, the multidisciplinary team would have had better information on which to plan Rachit’s care. In any such case, the assessment points are during the woman’s booking, pregnancy, labour and birth as well as during the postnatal period.

Booking records: on reviewing Advika’s notes, these had been completed thoroughly and clearly. Her blood group and Rhesus factor were recorded, as was the ethnicity of her husband.

Missed opportunities for appropriate intervention by all members of the health care team are clear. At any stage, questions needed to be asked about the early onset of jaundice of less than 72 hours (NICE 2016), the blood group of the baby and consideration of a differential diagnosis such as G6PD.

Transfer from hospital to home: Transferring the baby to the community from the hospital unit is beneficial to mother and baby but does require appropriate support. The midwife can follow up the baby in its new setting by providing continuity of care.

This was even more important in the care of Rachit, as jaundice had become evident at less than 72 hours. This should have instigated an immediate screening using a transcutaneous bilirubinometer (TcB) and may have required a diagnostic serum bilirubin (SBR). At this point, the management would have been assisted by consultation with a senior neonatologist, a plan of care and management agreed and recorded.

It is important to recognise that Rachit is an individual whose needs are not static and at this point in his life, he required continual assessment by the midwife with appropriate referral.

An assessment should have been completed to decide whether he could safely be transferred home or whether he required longer in the hospital setting. Whatever the plan of care, the whole multidisciplinary team needed to work with the mother and family to ensure that the care and management was tailored to Rachit’s needs. Any changes to his physiological well-being should have triggered a swift response and appropriate action taken if required.

Lack of communication/action plan: Advika and Rachit had different members of staff undertaking the transfer home. Rachit had the 72 hour assessment by a junior doctor in the morning, and the midwife who transferred/discharged Rachit home later on in the
Achieving seamless care… Can we?

Toula gave birth to baby Maria at 37 weeks’ gestation, weighing 3.8kgs. Maria had an Apgar score of nine and is now eight hours of age and her mother wishes to go home.

Maria was assessed and transferred home by the midwife, who was able to produce an individualised care plan into the Red Book and transfer documentation to meet the baby's needs following the transfer home. This plan was discussed with the mother, Toula, and she was provided with contact information should she have any concerns about herself or Maria.

The midwife noted that Toula is of Mediterranean heritage, as is her partner – therefore Maria will be at higher risk of G6PD deficiency and also, due to Maria’s blood group O positive, consideration was given to the risk of ABO incompatibility.

The transfer home plan took into consideration the issue that Maria was in transition from fetal to postnatal life. A visit to support

Case study 2

Toula gave birth to baby Maria at 37 weeks’ gestation, weighing 3.8kgs. Maria had an Apgar score of nine and is now eight hours of age and her mother wishes to go home.

Maria was assessed and transferred home by the midwife, who was able to produce an individualised care plan into the Red Book and transfer documentation to meet the baby’s needs following the transfer home. This plan was discussed with the mother, Toula, and she was provided with contact information should she have any concerns about herself or Maria.

The midwife noted that Toula is of Mediterranean heritage, as is her partner – therefore Maria will be at higher risk of G6PD deficiency and also, due to Maria’s blood group O positive, consideration was given to the risk of ABO incompatibility.
the mother to ensure that Maria was cared for in the appropriate thermal environment, and provision of support for Toula with breastfeeding if necessary was agreed. This provided an opportunity to physically assess Maria to exclude duct dependent disease and jaundice (as both parents are Italian). The midwife scheduled a community midwife visit in the next 24 hours after transfer.

Toula and Maria were visited by the midwife at 32 hours after Maria’s birth. Toula was well and had no problems. The midwife measured Maria’s serum bilirubin using her bilirubinometer and this identified that Maria was showing a bilirubin level one box below the phototherapy line. The midwife was able to contact the neonatal registrar for a discussion of Maria’s tests and assessment.

The discussion and plan of care were shared with Toula, and Maria was then admitted to the transitional care unit with her mother for continued care which included 48 hours of phototherapy. Maria responded well and, as breastfeeding was progressing well, she was transferred back home at six days of age.

Mother and baby were never separated, and after a postnatal review with Toula, the mother reported that she felt well-informed and supported throughout.

Later – Maria is progressing well, and has shown no problems following her jaundice. Breastfeeding is well-established, and Maria is gaining weight well.

In case study 2, the care given to Maria and her family was designed to be reliable and effective. It was obvious that the care provided was seamless between the team of midwives, doctors and ambulance service which was flawless and integrated with the relevant professional care. At all stages staff were informed and updated on any changes that were occurring so that services could be ready for use. This enabled Maria and her family to receive the necessary care swiftly and effectively without any delays or gaps. In follow up, Maria has had no residual problems and is reaching all expected milestones.

Discussion

The contrast between both case studies is sharp and could be in two completely different services. The second case study speaks of thought through care, involving the mother and family, and the drawing up of an effective action plan, using information gleaned from the mother’s past history and including the baby’s own history. This type of care needs to be subscribed to by the team at every level. It may appear effortless to Toula and her family, but does require planning, communication and leadership.

Organisational leaders need to work together to develop a joint vision as well as articulating how it can happen in everyday practice. Creating a compelling narrative that effectively describes the vision and purpose of joining up services, making it real and relevant for all staff and stakeholders, is a really important communication task. Leaders need to understand how the changes will impact on all staff and ensure that ‘patterns’ which may manifest in cultural and behavioural challenges are considered alongside any structural, business and process components.

It may be useful for community midwifery teams to consider that the transfer/discharge plan has been reviewed by the team leader, and allocated to the caseload lead midwife, who will provide continuity of care for at-risk newborns in a given team. Pathways of communication between the community and hospital will enable easy access back into hospital care, for investigations and treatment, and to avoid delays in management of care.

Tools for seamless care

Education of the practitioner in neonatal care

Care of the newborn has progressed and today’s practitioners require in-depth knowledge of physiology, pathology, behaviour and the psychological needs of each baby from birth to the immediate and subsequent neonatal period. Education of the midwife is spasmodic and is being reviewed by the Nursing and Midwifery Council. It is hoped that the pre-registration midwifery curriculum will be adapted to increase knowledge of the newborn in order to practice and provide scientific, sensitive and compassionate care for each baby and his/her family in today’s world. There are a variety of educational and developmental tools available for updating, including the RCM (2015) electronic learning module.

Effective use of time and planning

In today’s health service, time is always at a premium, and this can lead to relying more on routine and on sometimes swift overview assessment. However, a little investment of time in assessment and planning does normally pay dividends, as could be seen in the second case study.

Guidelines and evidence

The most recent NICE (2016) guidelines are a critical tool for the whole multidisciplinary team, and includes the underpinning evidence for practice, and an information sheet for parents (NICE 2010).

Why Atain?

Atain is an acronym for Avoiding Term Admissions Into Neonatal units and is a programme of work led by the NHSI in collaboration with clinical experts. The programme offers insights, recommendations and practice points to reduce harm leading to avoidable admission to neonatal units for infants born at term ie ≥ 37-weeks’ gestation. The Atain programme is focusing on four key areas relating to term admissions:

- Respiratory
- Hypoglycaemia
- Jaundice
- Asphyxia.
Reducing the number of avoidable term admissions into neonatal units is a priority for the NHS. The patient safety team within NHSI are working in collaboration with the Atain working groups using intelligence gathered from a variety of resources. Insights gleaned from triangulation of findings from patient safety reports, hospital admission data and litigation claims indicate that a system wide approach to addressing the issue of term admissions is required.

Term infants form the largest proportion of all babies admitted to neonatal care with latest figures showing that 60% of all neonatal unit admissions are full-term babies (NHS Improvement 2017). Crucially, the work programme recognises that admission of some full-term babies is entirely appropriate and that failure to admit these babies could lead to harm. However, there is also the recognition that improved understanding of modifiable factors and action to address these factors can lead to a reduction in avoidable admissions.

As well as reducing harm, this work programme aims to reduce separation of mother and baby. When maternity and neonatal teams work together, outcomes for babies, mothers and families are optimised and separation avoided. The care of mothers and babies is currently transferred between hospital and community teams early in life and it is inevitable that many babies will require assessment of jaundice with some requiring treatment in hospital (Luciano 2015).

So far the work has identified areas which have led to high numbers of readmissions of babies to neonatal units (NHS Improvement 2017). This was not just costly in financial and human terms, but meant that mothers and babies were often separated, with mothers and families exposed to further stress and anxiety. Some problems could have been identified more quickly to reduce harm to the baby and family. Whenever possible, treatment should be given promptly in a safe and baby friendly environment and babies should remain with their mothers. Only babies requiring double phototherapy and intravenous infusion of fluid, or those who are ill as well as jaundiced, require admission to neonatal units.

The work of Atain will next liaise with Health Education England to produce an i-Learning package for all professionals that support the care of the newborn.

Conclusion
This article has presented the issue of neonatal jaundice and its contemporary management using two case studies and has drawn on the work of Atain to illustrate how practice could be improved by using a seamless approach to care.

'Joined-up' care does not always require extra resources; it requires leadership, the will, some good ideas and a determined and disciplined approach to implementation. Most of all it requires the health care team to create a sense of unity and common purpose amongst those who deliver the different elements of care, so that each practitioner sees themselves as a united whole, delivering great care to patients. In an era of economic challenge, joining-up care is one of the most effective strategies to improve productivity and reduce costs whilst improving quality.

Alongside good leadership and effective use of resources, this also calls for a commitment to high-quality, thoughtful midwifery care. As midwives, this challenges us to ensure good postnatal and neonatal care, question which actions are required, and to provide continuity towards truly personalised care (NHS England 2016). It is also critical to use available personnel to closely examine the mother’s history and records, swiftly identifying any possible risk factors, and design dynamic and individualised plans of care. This enables care and management to be tailored to the mother’s and baby’s needs, and allows for swift action or intervention should it be required, with limited adverse effects on the maternal-infant relationship as well as reducing unnecessary admissions to hospital.

Acknowledgement
This paper is based upon some of the work of the Atain group. The author would like to acknowledge the contribution made by the Atain jaundice working group in the completion of this article.

Stephanie Michaelides, Senior Lecturer, Middlesex University, Co-Chair to Atain Jaundice Working Group.

References

Department of Health (2000). An organisation with a memory: report of an expert group on learning from adverse events in the NHS chaired by the Chief Medical Officer. London: DH.


Original article. © MIDIRS 2017.