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Perceptions of neonatal jaundice and evidence-based care: Interviews with 41 Australian health professionals

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Title: Perceptions of neonatal jaundice and evidence-based care: Interviews with 41 Australian health professionals

Abstract

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality. Although severe adverse outcomes, such as hyperbilirubinaemia and kernicterus, are uncommon in high-income countries, these outcomes do occur, have enormous lifelong personal, health and social costs, and may be preventable. Evidence-based practice commonly relies on clinical guidelines however their implementation can be difficult. Five contexts affecting implementation include the clinical guidelines themselves, issues within health systems, the socio-political context, health professionals, and patients. This paper focuses on the perceptions of Australian health professionals involved in the management of neonatal jaundice.

Methods

Interviews with 41 Australian health professionals from a range of disciplines and care settings using a qualitative descriptive approach and content analysis to identify themes describing experiences and perceptions.

Results

Gaps in the implementation of evidence-based care to manage neonatal jaundice identified related to issues with professional boundaries, competing priorities and poor understanding of neonatal jaundice. Several health professionals felt they knew what was needed to implement best practice care through improved education and standardised policies and protocols but did not know how to make such improvements happen.

Conclusions

Multiple barriers to evidence-based neonatal jaundice management create gaps in care, including in clinical guidelines. Implementation strategies for evidence-based practice need to take account of the experiences of health professionals and the challenges they face. Such strategies need to focus on improving collaboration between different disciplines for the well-being of those needing care. In

the case of neonatal jaundice management, consideration is also needed in how to raise awareness of the importance of avoiding severe adverse outcomes, even when they might be rare, and how this might be done. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice among health professionals is essential.

Strengths and Limitations of the Study Methods

- Several health disciplines across geographical and work settings in Australia were involved in this study, providing a broad range of perspectives.
- Limitations include the extended period for data collection and analysis, which were driven by practical constraints. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.
- The decision not to record interviews encouraged participation. All interview scripts were verified by interviewees.
- The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable.
- This study presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.

Keywords

Neonatal jaundice, kernicterus, evidence-based care, clinical practice guidelines, implementation science

What is already known on this topic

Severe adverse neonatal outcomes associated with neonatal jaundice are rare in most high-income countries, but they do occur. Little is known about the perceptions of health care professionals in managing severe neonatal jaundice.

What this study adds–

This study identifies gaps in the management of neonatal jaundice in Australia and possible ways to improve awareness and care when severe neonatal jaundice occurs.

How this study might affect practice and policy

The study highlights the challenges to evidence-based care when issues are complex and adverse events are rare. Strengthening surveillance of adverse perinatal outcomes, including severe neonatal jaundice, would inform guideline development, associated resource decisions, and health professional training.

Background

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality.(1-4) In 2016, neonatal jaundice accounted for over 1300 deaths per 100,000 livebirths and was ranked seventh among all causes of death in the early-neonatal period.(2-4) Severe adverse outcomes associated with neonatal jaundice are uncommon in high-income countries, but do occur and may be preventable, creating an ongoing challenge for health care standards.(4, 5) In Australia, the findings from a surveillance study conducted between 2010 and 2013 to determine the incidence of extreme hyperbilirubinemia (9.4 per 100,000 livebirths) and bilirubin encephalopathy (0.6 per 100 000 livebirths) in term and near-term neonates,(6) showed that at least 20 to 25 babies are affected every year. Extreme neonatal hyperbilirubinaemia can result in long-term neurological dysfunction, including brain damage and even death.(4-10)

Deficiencies in the care of jaundiced newborns have been identified as contributing to adverse outcomes.(11-14) Care deficiencies need to be minimised, particularly when adverse consequences have enormous personal costs as well as lifelong health and social costs.(14, 15) Modern health care, built on evidence-based practice, commonly relies on clinical guidelines. However, implementation of clinical guidelines can be difficult. A meta-review of 25 systematic reviews exploring the barriers and facilitators to guideline implementation(16) identified five contexts showing its complexity: the clinical guidelines themselves; the health system; the socio-political context; health professionals; and patients.

While the role of health professionals is critical to evidence-based care, their experiences in some areas of practice are largely unknown. This paper explores the perceptions of Australian health professionals involved in the management of neonatal jaundice. It is part of a mixed methods study that includes assessment of neonatal jaundice guidelines used across Australia,(17) which are based on international guidelines(18-20) that have changed little over the past decade.(17)

Methods

A qualitative descriptive design to explore health professionals' experiences and perspectives(21, 22) used semi-structured interviews and an interpretivist approach(23) to gain understanding of the experiences of health professionals across Australia with the care of jaundiced newborns. A purposive maximum variation sampling process was adopted.(24) Potential participants were approached in writing either directly, for those in private practice, or indirectly via institutional leaders for those working in maternity hospitals, universities, and government departments. Recruitment progressed to ensure a mix of disciplines, geographical areas and settings and continued until data saturation was achieved and no new themes emerged. Data were collected over two years, between August 2011 and December 2013. Interview topics included personal preparation and experiences of neonatal jaundice; knowledge of jaundice-related neonatal morbidity, associated policies and guidelines; and thoughts about any practice adjustments needed for better neonatal jaundice management. Interviews were conducted either face-to-face or by telephone and ranged from 20 to 120 minutes in duration (average 65 minutes). Interviews were not audio-recorded. Detailed notes were taken, including verbatim comments. Interview scripts were completed after each interview to minimise recall bias(25) and returned to participants for verification. This approach aimed to facilitate participation by recognising sensitivities with audio recordings about clinical care. A field journal was maintained to assist in validation and consistency.(26)

Following verification by participants, interview scripts were imported into NVivo qualitative research software (NVivo 10 and 12 for Mac, QSR International) for thematic content analysis.(27) All scripts were thoroughly read and re-read to ensure accuracy, gain an overall impression of the data and to identify recurring information and variations. The preliminary analysis included coding for categories and major themes according to the different types and contexts of practice. Preliminary codes were refined as coding progressed and as themes emerged. Themes were tested

within and between cases to ensure integrity of the theme boundaries. Coding was checked several times, including independent confirmation by two experienced researchers who read the first five interviews and by a third researcher who compared final codes against a data sample. Illustrative quotes were identified by discipline.

Reflexivity was critical as the first author intersected with the data in several ways. The study was part of doctoral studies motivated by personal experience as a mother of a child diagnosed with kernicterus and also as a nurse and policy and program advisor. Ezzy (2002) observed that personal experience typically shapes the definition of a research problem(28) and how data are collected and analysed; and so is also a data source about the research problem (2002: 153). A mindset of 'conscious partiality'(1999: 20)(29) was cultivated.

Ethics approval was given by the university Ethics Committee (FHEC11/47), and by respective health and medical research committees throughout Australia. Participation was voluntary and informed consent was required prior to all interviews. No one withdrew.

Patient and public involvement

The approach taken for this research was to focus on practice aspects of evidence-based care rather than look at the impact of current practice on infants and families. Study participants were all health professionals who provided informed consent. Plans for dissemination of results were relayed to all participants and included publication in a journal and presentation in various fora.

Results

Participants

Forty-one health professionals from six broad discipline areas were interviewed (nursing [3], midwifery [15], medicine [12], pathology [2], clinical education [6], and policy development [8]). The 12 doctors came from four different specialty areas (general practice/obstetrics, paediatrics and neonatology). The majority (66%) had 10 or more years professional experience. Five participants

worked across state boundaries (12%). Seven participants working in policy development also had clinical roles.

Findings

Two major themes and explanatory sub-themes were found (see Figure 1).

Falling through the gaps

This theme reflected views and reported experiences that some neonates were "slipping through the net" as a consequence of their neonatal jaundice management. Four explanatory sub-themes were associated with this theme: professional boundaries; blindness to possibility of adverse outcomes; competing professional development priorities; and unintended consequences.

Professional boundaries

Gaps arising from issues related to professional boundaries were revealed across different professional groups and included limitations in knowledge and experience. Relationships and communication appeared to be affected. Knowledge gaps and lack of experience meant adverse outcomes were possible. For example, several doctors linked lack of knowledge in junior doctors as a risk, for example:

> "...Trying to get exposure to cover all aspects of neonatal care has been an ongoing issue. Learning about neonatal jaundice is not in any formal way mandated in training of general paediatricians." (neonatologist_C)

Midwives, including educators and those involved in policy development, also linked lack of adequate knowledge and clinical experience to poorer outcomes. One midwife summed up the situation this way:

> "…. [Neonatal jaundice] is probably not managed that well…. there is the potential for it to get missed….there is no surveillance strategy…. there is a deficit in the learning…. junior doctors lack experience; they are not good at putting the picture together; they may not

> even have seen the baby….midwives are generally not able to sign pathology slips….If the baby is starting to get jaundice within 24 hours – will call the paediatrician to look at the baby; we monitor – see how it goes...make sure feeding is happening frequently…..If early discharge –will home visit…….It might not be until the home visit that the midwife sees that the baby is bright yellow…..Parents may think the baby has olive skin. Parents are not trained to look and assess…. Guidelines and protocols are only looked at when an issue comes up." (Midwife_C)

Professional boundaries rising from poor relationships and poor communication created potential gaps in care, particularly when role conflict existed. The most common example was differences between medical and midwifery paradigms, sometimes described as interventionist and non-interventionist approaches. The impact was evident in descriptions of assessment approaches. Midwives referred to using "intuition" or "instinct" as part of their professional assessment. In contrast, medical practitioners were likely to report erring on the side of caution for both testing and treating, "just in case". As one said:

> "...we have to do that for fear of kernicterus. At a serum bilirubin level of 310, the baby receives treatment. It is not necessarily the right thing to do but don't want to miss pathological jaundice." (Paediatrician_C)

Tension between different professional relationships was evident in several interviews, such as between pathology personnel and clinical staff:

> "There have been specific problems measuring bilirubin for a long time; trying to get it right; there is a combination of things; measurement, early discharge, lack of knowledge, lab measuring delay, haemolysed samples. Lab error is unlikely; if there is a mistake it is repeated." (Pathologist_C)

Professional boundaries affecting care were also reported within speciality groups in the same discipline, for example:

> "There are conflicting views between the medical consultant and the paediatrician… for example in a baby with high SBR [serum bilirubin] the medical consultant will say put the baby under two lights; the paediatrician will visit later and say 'no just use one light'." (Midwife_A)

Professional boundaries affecting communication were most evident in accounts of absent feedback when neonatal jaundice was suspected, affecting confidence among less experienced professionals when potential cases were suspected.

> "...if you are seeing newborns babies all time, your skills are better, your assessment skills are better, when compared to midwives who only occasionally work with babies; you have a different perspective. There is a potential for over-reacting and under-reacting. I tend to overreact." (Educator, maternal and child health/midwife_C)

Blindness to possibility of adverse outcomes

Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in Australia, including one paediatrician, who despite reporting experience with many jaundiced infants, had had no direct experience of adverse outcomes, so felt one was unlikely. Similarly, one midwife explicitly questioned whether a kernicterus diagnosis was possible in Australia. Several others commented on the rarity of severe neonatal jaundice in Australia, also raising doubts about whether serious adverse outcomes occur.

Knowledge of adverse outcomes associated with neonatal jaundice was not considered important in Australian conditions according to some interviewees. When talking about their clinical education, the term "kernicterus" was recalled by some midwives as a "scary thing" or reportedly mentioned

"in passing". Despite several comments about higher proportions of Asian women readmitted with jaundiced babies, only five participants (two paediatricians, a neonatologist, midwife and neonatal nursing educator), considered the needs of genetic diversity and ongoing population changes, aware of a clinical trial conducted in one health service.

Very few participants recognised the increased risk for First Nation Australians. One paediatrician who worked in an area with a higher proportion of First Nation residents and those with Asian backgrounds, questioned the association with skin colour, commenting:

> "One cannot make assumptions about ethnic heritage; there has been much exchange of genetic material over the years. Pigmentation is not fully developed in the first few weeks of life." (Paediatrician_A)

Competing professional development priorities

Almost all health professionals acknowledged difficulties in keeping abreast of research evidence; some felt individuals were responsible to keep up-to-date, but most relied on others to make research information available.

> "I don't go looking for [information, literature] " (Midwife_B)

Participants who felt unable to keep up with research, also talked about other priorities, lack of access to resources or the size of the challenge:

> "Keeping up to date with research is difficult. A significant number of midwives don't do it well. If outside the system, it is difficult, if not enrolled in University. How many journals can you subscribe to? It costs money. You rely on Google. You give up. Access is difficult. Enrolling in University costs money and you need time" (Midwifery educator/consultant_C)

Most participants agreed that neonatal jaundice was one of many conditions that health professionals need to know about. Several acknowledged lack of understanding of normal physiology or differences between physiological and pathological jaundice. Overall, professional development opportunities on neonatal jaundice care were limited.

Unintended consequences

Systemic issues within service delivery and organisations revealed involved unintended consequences, such as the absence of mechanisms to document adverse effects. Some participants pointed out that without such information measuring impact is difficult. Participants cognisant of potential consequences remarked:

> "One may not know the outcome of severe neonatal jaundice for years. Hearing loss may be evident within hours." (Pathologist_D&F)

> "Common reasons for readmission are G6PD, ABO incompatibility, dehydration, bruising. There is less awareness around these. The number of babies readmitted is not coded as separate. It is not easy to get this information." (Neonatologist_E)

Many interviewees commented on the potential cost of testing, which was commonly considered in terms of over-testing and over-treatment. One participant said:

> "You would need to test every parent and child. Test fathers, test cord blood. Per baby it would be $150 extra assuming 200,000 babies born per year – there would not be much benefit." (Paediatrician_C)

In contrast, another participant felt it would be cheaper to test every baby "as then the health service cannot be sued….". Several doctors and a pathologist raised the potential costs associated with one missed case.

Early discharge of mothers and babies was commonly identified as a potential problem for neonatal jaundice identification. All participants working in hospital postnatal wards identified early discharge as a barrier to developing better clinical knowledge:

> "There is a concern about early discharge. It is a problem in Australia. It seems greater [than in other countries]. Our women get kicked out. Monitoring is variable across Australia. What is the monitoring process?" (Neonatologist_C)

Issues arising from early discharge included variability in post-discharge care, where neonatal jaundice management was variously described as "haphazard" or dependent on "competing

demands" with "no dedicated surveillance" measures in place. While one neonatologist described a robust community system, numerous others, including other neonatologists, did not concur:

> "Need better way of streamlining taking serum bilirubin levels at home. Would need to report to the registrar. All midwives at home should perhaps carry a bilirubinometer. Institutions vary – each hospital will have its own policies. …. Need resources for daily home visits for a minimum of three days until the maternal and child health nurse kicks in; need lactation support." (Neonatologist_C)

Contributing to uncertainty about patient care trajectories was growing reliance on a casualised workforce, particularly in midwifery, which was seen to affect skill and knowledge development:

> "Midwives, we are reliant on them for recognising and assessing; they are a mixed bunch; quite a number do shifts in post-natal ward. They are semi-deskilling themselves. Not keeping up to date. They occasionally take a while to properly communicate regarding jaundiced cases." (Paediatrician_C)

Poor knowledge of neonatal jaundice among health professionals also affects communication with parents about the condition. Some participants pointed out that no specific information for parents existed while others were concerned not to overwhelm parents with more information than needed.

We know what should happen – but how?

The second major theme was the perception among participants that while they knew what was required to improve care, they were unsure how to achieve those changes.

Improvements in education and training

Almost all participants expressed needs for better education, particularly for midwives and junior doctors and parents. Several participants suggested that links between curriculum, guidelines and clinical practice were missing:

> "There was a little bit of education around neonatal jaundice during medical training; not thorough; not much at all. It should be covered better especially for GP obstetricians. My

general knowledge is not great about neonatal jaundice. There is a midwife educator….. maybe should have a bigger role. This may include keeping in touch with current research publications; to let us know what is out there." (GP/Obstetrician_C)

Guidelines were frequently portrayed as ineffective tools for evidence-based care. The development and update of clinical guidelines was described as time-consuming. Several participants reported that guidelines were not included in their professional training and were considered difficult to navigate and not specific enough to be useful.

"Guidelines. Don't use them, don't look at these." (Midwifery educator_C)

"We need concrete guidelines around when to take SBR [serum bilirubin], for example if the jaundice is below the belly button, you need to do a blood test. Need to take way subjectivity." (Educator/maternal and child health coordinator/midwife_C)

Standardised policies and protocols

Most participants described policies and processes relating to neonatal jaundice management as variable and viewed as significant barriers to achieving necessary changes. Underpinning concerns were inconsistent or confusing language. Several participants pointed to examples of how different types of jaundice were described and assessed. For example, "clinical jaundice" was used to describe jaundice requiring a blood test and "jaundice" used when "severe jaundice" meant. Conflation created confusion—and, in the views of some participants—diminished the importance of severe bilirubin among clinicians.

While calls for consistency in neonatal jaundice management came from across discipline areas, all conceded that reaching agreement was difficult. Some health professionals felt there was already multidisciplinary collaboration in policy and guideline development, while others believed such collaboration to be missing. Challenges included a "them-and-us" mindset, including between tertiary centres and smaller services, and even siloed approaches within tertiary centres:

The wordiness of guidelines was frequently criticised. Poor accessibility exacerbated dissatisfaction. Participants using guideline websites found navigation difficult. The majority felt current guidelines needed to be reviewed, updated, or in some views, developed. Some called for more prescriptive guidelines "to rule out grey areas".

> "Guidelines – they are not easy to find; website is not intuitive, guidelines are under "metabolic" (section). At 3am in the morning, when everyone is tired, (guidelines are) hard to find. On-line - so many guidelines. Use most recent but many are out of date." (Paediatrician_A)

Discussion

In looking at the experiences of Australian health professionals with neonatal jaundice management, challenges with implementing evidence-based care have been revealed. Several gaps in effective implementation were identified alongside feelings of inability to enact effective change. These issues are likely to apply beyond neonatal jaundice management to the wider use of evidence-based care.

Four of five contexts relevant to clinical practice guideline implementation identified in the meta-review exploring barriers and facilitators,(16) were evident in this study: the clinical guidelines themselves, the health system, the socio-political context and health professionals. This study also identified particular challenges for evidence-based care when adverse events are rare.

Consistent with the most frequently mentioned barrier to guideline implementation in the meta-review(16) were clinical guidelines themselves, particularly with lack of clarity. Other issues such as problems with credibility and day-to-day practice feasibility were also present and appear to be related to inconsistency, lack of standardisation, and unnecessary wordiness. Poor accessibility to guidelines exacerbated dissatisfaction and fuelled scepticism about guideline usefulness.

Barriers identified in the health system context in the meta-review, lack of time, resources, and specialised personnel(16) were also raised in this study. Two other health system developments were linked to possible unintended consequences for neonatal jaundice management. Early discharge practices were directly attributed to creating difficulties for timely diagnosis. Participants pointed out that in the context of early discharge greater need for parent awareness of neonatal jaundice exists. Predictors of discharge 'readiness' explored in a US study involving 185 mothers, suggest that potential problems could be ameliorated by good pre-discharge education practices, although education depends on what, and how, nurses are able to teach mothers before leaving hospital.(30) Workforce casualisation was another health system issue identified as a potential barrier to good care for midwives in particular, reducing opportunities to acquire and reinforce neonatal jaundice knowledge.

The political and social context identified in the meta-review included barriers such as absent or poor leadership, teamwork difficulties; and lack of agreement between colleagues around guideline implementation.(16) In this study, issues of leadership and implementation agreement were also raised although interprofessional conflict was more frequently reported. Problems with interprofessional boundaries in health care can be found across the literature. For example, professional boundaries have impeded attempts to deliver best practice in unintended or unexpected ways. In Wales, an attempt to reduce unnecessary childbirth interventions by promoting midwife-led care using a clinical pathway found stricter boundary delineation actually reduced the scope of midwifery practice.(31) Whereas in Australia, inter-professional differences affected communication and information transfer in study looking at child and family health services.(32)

Key to resolving professional conflicts is understanding that divergent perceptions do arise between disciplines, and even within the same discipline. This was evident in this study where the inclusion of several discipline groups found conflicting paradigms guiding care. This is not unique to Australia or to neonatal jaundice management. In a large Swedish university hospital study, existing power

relations impeded effective professional teamwork.(33) Awareness of the interrelationships between professions, particularly when professional knowledge and work overlap, needs consideration in planning care and in developing guidelines. Interprofessional relationship issues, characterised by competition and conflict, seem central to professional identity.(34) They need ongoing attention. Interdependent professions can experience constant conflict when continuous engagement related to expert labour and jurisdictional disputes exist. Resolution, when it does occur, tends to be temporary and followed by renewed disturbances.(34)

Gaps in neonatal jaundice knowledge were acknowledged in this study and in other studies and other countries. For example, in the USA, a cross-sectional study of paediatricians(35) found significant uncertainty in relation to identifying risk factors and using diagnostic approaches to manage neonatal jaundice. Congruent findings were also found in a root-cause analysis of 125 full-term infants with acute bilirubin encephalopathy voluntarily reported to the Pilot USA Kernicterus Registry (1992 to 2004), where the progression to hazardous bilirubin levels was attributed to the inability of multiple health professionals across multiple sites to identify at-risk infants or to manage severe hyperbilirubinemia in a timely way.(36)

An important finding of this study, unrelated to previous studies in this area, relates to particular challenges when adverse events are rare. Low case frequency may give clinicians false confidence that processes are working. The incidence of severe neonatal outcomes arising from extreme neonatal hyperbilirubinemia in Australia, when reported by clinicians, is around 10 per 100 000 live births.(6) While international comparisons are difficult due to definitional differences, including serum cut-off levels, gestational age ranges, and methods of data collection, a Swedish study that identified cases of kernicterus (bilirubin encephalopathy) through medical records, found almost half were most likely avoidable. These were attributed to failure to adhere to best practice, including untimely or no bilirubin screening, misinterpretation of bilirubin levels, and delayed or failure to initiate treatment.(37) That some health professionals in this study dismissed the possibility of

severe adverse outcomes in Australia is concerning, particularly as lack of awareness of the possibility of poor outcomes can be the most significant barrier to improving patient safety.(38) The absence of ongoing reporting of all adverse neonatal outcomes, including severe neonatal jaundice, appears to be critical. In the absence of adverse outcome data, there is little opportunity for health professionals to build knowledge or to make reasonable cost-benefit judgements.

Strengths and Limitations

Both strengths and limitations are present. Several health disciplines across geographical and work settings in Australia were involved, providing a broad range of perspectives. Limitations include the extended period for data collection and analysis, which were driven by practical constraints. The study was conducted over a staggered period, somewhat mirroring the process of guideline development. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.(17) The slow pace of analysis also gave time for reflection. The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable. The decision not to record interviews may be viewed by some as a limitation but also encouraged participation and all scripts were verified by interviewees. Interview scripts written directly after interviews have been shown to have similar quality to audio-recorded transcripts.(25) Despite its limitations, this paper presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.(39)

Conclusion

Multiple barriers exist in evidence-based care related to neonatal jaundice management. Gaps in care exist as clinical guidelines alone are not sufficient to support health professionals deliver evidence-based care in the complex contexts in which they work. Implementation strategies for evidence-based practice need to take account of health professionals' experiences and the challenges they face. Implementation strategies for neonatal jaundice management need to

consider how to raise awareness of the importance of avoiding severe adverse outcomes, despite their rarity, the consequences are devasting. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice is essential. Gaps in evidence-based practice arise even when clinical guidelines exist, and health professionals do not know how to address them.

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Figure 1- Analysis of 41 interviews with health professionals: two major themes and explanatory sub-themes.

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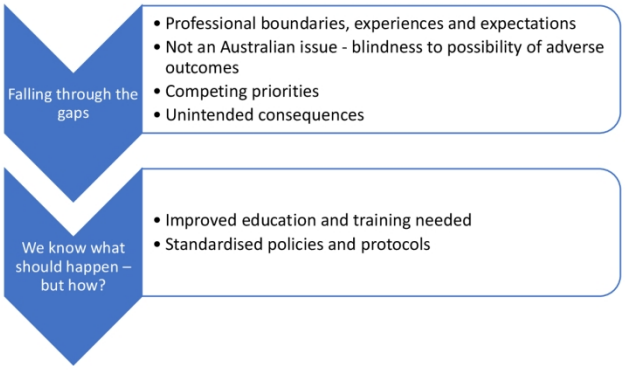

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Title: Experiences with neonatal jaundice management in hospitals and the community: Interviews with Australian health professionals

Abstract

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality. Although severe adverse outcomes, such as hyperbilirubinaemia and kernicterus, are uncommon in high-income countries, these outcomes do occur, have enormous lifelong personal, health and social costs, and may be preventable. Evidence-based practice commonly relies on clinical guidelines however their implementation can be difficult. Implementation of neonatal jaundice care has been adversely affected by issues with professional boundaries, competing professional priorities and poor understanding of neonatal jaundice. This paper focuses on the perceptions and experiences of Australian health professionals involved in the management of neonatal jaundice.

Methods

Using a qualitative descriptive approach, semi-structured interviews were undertaken to gain understanding of the experiences of health professionals in Australia across the scope of care for jaundiced newborns through an interpretivist approach and to identify possible gaps in the delivery of evidence-based care. Health professionals from a range of disciplines and care settings were recruited by purposive maximum variation sampling. Interviews were conducted face-to-face or by telephone with detailed notes taken and a field journal maintained. Interview scripts were verified by participants and imported into NVivo software. Data were analysed for major themes according to type and contexts of practice.

Results

Forty-one health professionals from six broad discipline areas were interviewed. Two major themes and explanatory sub-themes were found. The first theme, *Falling through the gaps*, highlighted gaps in evidence-based care, as described by four explanatory sub-themes: professional boundaries; blindness to possibility of adverse outcomes; competing professional development priorities; and unintended consequences.

The second major theme, *We know what should happen – but how?,* described participant perceptions that it was known what was required to improve care but how to achieve such changes was unclear. The two sub-themes are: improvements in education and training; and standardised policies and protocols.

Conclusions

Multiple barriers to the provision of evidence-based care related to neonatal jaundice management are experienced by health professionals in Australia. Clinical guidelines are not sufficient to support health professionals deliver evidence-based care in the complex contexts in which they work. Implementation strategies for evidence-based practice need to take account of the experiences of health professionals and the challenges they face. Such strategies need to focus on improving collaboration between different disciplines for the well-being of those needing care. In the case of neonatal jaundice management, consideration is also needed in how to raise awareness of the importance of avoiding severe adverse outcomes, even when they might be rare, and how this might be done. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice among health professionals is essential.

Strengths and Limitations of the Study Methods

- Several health disciplines across geographical and work settings in Australia were involved in this study, providing a broad range of perspectives.
- Limitations include the extended period for data collection and analysis, which were driven by practical constraints. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.
- The decision not to record interviews encouraged participation. All interview scripts were verified by interviewees.

- The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable.
- This study presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.

Keywords

Neonatal jaundice, kernicterus, evidence-based care, clinical practice guidelines, implementation science

Background

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality.(1-4) In 2016, neonatal jaundice accounted for over 1300 deaths per 100,000 livebirths and was ranked seventh among all causes of death in the early-neonatal period.(2-4) Severe adverse outcomes associated with neonatal jaundice are uncommon in high-income countries, but do occur and may be preventable, creating an ongoing challenge for health care standards.(4, 5) In Australia, the findings from a surveillance study conducted between 2010 and 2013 to determine the incidence of extreme hyperbilirubinemia (9.4 per 100,000 livebirths) and bilirubin encephalopathy (0.6 per 100 000 livebirths) in term and near-term neonates,(6) showed that at least 20 to 25 babies are affected every year. Extreme neonatal hyperbilirubinaemia can result in long-term neurological dysfunction, including brain damage and even death.(4-10)

Deficiencies in the care of jaundiced newborns have been identified as contributing to adverse outcomes.(11-14) Care deficiencies need to be minimised, particularly when adverse consequences have enormous personal costs as well as lifelong health and social costs.(14, 15) Modern health care, built on evidence-based practice, commonly relies on clinical guidelines, that are developed from the best available evidence, even when such evidence is weak. Implementation of clinical guidelines can be difficult. A meta-review of 25 systematic reviews exploring the barriers and facilitators to guideline implementation(16) identified five contexts showing its complexity: the clinical guidelines themselves; the health system; the socio-political context; health professionals; and patients.

While the role of health professionals is critical to evidence-based care, their experiences in some areas of practice are largely unknown. The focus of this paper is the management of neonatal jaundice, which relies on the use of clinical guidelines, and where rare, severe, adverse outcomes do occur. This study aims to explore health professionals' experiences and perspectives of neonatal jaundice management in Australia to identify possible gaps in the delivery of evidence-based care. This study is part of a mixed methods study that includes assessment of neonatal jaundice guidelines

used across Australia(17). These guidelines in Australia are based on international guidelines(18-20) and, as shown in a recent comparative review(17), have changed little over the past decade.

Methods

Using a qualitative descriptive design (21, 22), semi-structured interviews were undertaken to gain understanding of the experiences of health professionals in Australia across the scope of care for jaundiced newborns through an interpretivist approach (23) and to identify possible gaps in the delivery of evidence-based care. We considered evidence-based care to comprise the three elements nominated by Sackett (1996)(24): use of the best available research evidence; application of clinical expertise; and consideration of patient "predicaments, rights and preferences"(24).

A purposive maximum variation sampling process was adopted.(25) Potential participants were approached in writing either directly, for those in private practice, or indirectly via institutional leaders for those working in maternity hospitals, universities, and government departments. These leaders identified potential participants associated with neonatal jaundice care and forwarded information to them about the study, including consent forms to complete. Potential participants approached directly, including general practitioners, obstetricians, paediatricians, midwives in private practice and maternal and child health nurses, were also sent this information. It was anticipated that approximately 40 participants would be needed based on five participants from each State and Territory and the number of disciplines approached. Recruitment progressed to ensure the desired mix of disciplines, geographical areas and settings and continued until data saturation was achieved and no new themes emerged. (26) Data were collected over two years, between August 2011 and December 2013. Interview topics (see Supplementary material) included personal preparation and experiences of neonatal jaundice; knowledge of jaundice-related neonatal morbidity, associated policies and guidelines; and thoughts about any practice adjustments needed for better neonatal jaundice management. Interviews were conducted either face-to-face or by

telephone after participants provided written informed consent and ranged from 20 to 120 minutes in duration (average 65 minutes). Interviews were not audio-recorded. Detailed notes were taken, including verbatim comments. Interview scripts were completed after each interview to minimise recall bias(27) and returned to participants for verification. This approach aimed to facilitate participation by recognising sensitivities with audio recordings about clinical care. A field journal was maintained to assist in validation and consistency.(28)

Following verification by participants, interview scripts were imported into NVivo qualitative research software (NVivo 10 and 12 for Mac, QSR International) for thematic content analysis.(29) All scripts were thoroughly read and re-read to ensure accuracy, gain an overall impression of the data and to identify recurring information and variations. The preliminary analysis included coding for categories and major themes according to the different types and contexts of practice. Preliminary codes were refined as coding progressed and as themes emerged. Themes were tested within and between cases to ensure integrity of the theme boundaries. Coding was checked several times, including independent confirmation by two experienced researchers who read the first five interviews and by a third researcher who compared final codes against a data sample. Illustrative quotes were identified by discipline.

Reflexivity was critical as the first author intersected with the data in several ways. The study was part of doctoral studies motivated by personal experience as a mother of a child diagnosed with kernicterus and also as a nurse and policy and program advisor. Ezzy (2002) observed that personal experience typically shapes the definition of a research problem(30) and how data are collected and analysed; and so is also a data source about the research problem (2002: 153). A mindset of 'conscious partiality'(1999: 20)(31) was cultivated.

Ethics approval was given by the university Ethics Committee (FHEC11/47), and by respective health and medical research committees throughout Australia. Participation was voluntary and informed consent was required prior to all interviews. No one withdrew.

Patient and public involvement

There was no patient involvement in the study. The approach taken for this research was to focus on practice aspects of evidence-based care rather than look at the impact of current practice on infants and families. Study participants were all health professionals who provided written informed consent. Plans for dissemination of results were relayed to all participants and included publication in a journal and presentation in various fora.

Results

Participants

Forty-one registered health professionals working with jaundiced newborns in some way, were interviewed. Participants came from six broad discipline areas (nursing [3], midwifery [15], medicine [12], pathology [4], clinical education [6], and policy development [8]), and worked in a range of settings.

The 12 doctors came from four different specialty areas (general practice/obstetrics, paediatrics and neonatology). The nurses were involved in neonatal care, both within the hospital and in the community. The midwives worked in hospital and/or private practice, involving homebirth and/or postnatal care. The clinical education group included maternal and child health, neonatal care, and midwifery care. The majority of participants (66%) had 10 or more years professional experience. Five participants worked across state boundaries (12%). Seven participants working in policy development also had clinical roles. All eight participants in this group were employed by health organisations and were engaged specifically in the development of neonatal jaundice policy.

Findings

Two major themes and explanatory sub-themes were found: Figure 1.

Falling through the gaps

This theme reflected views and reported experiences that some neonates were "slipping through the net" as a consequence of their neonatal jaundice management. Four explanatory sub-themes were associated with this theme: professional boundaries; blindness to possibility of adverse outcomes; competing professional development priorities; and unintended consequences.

Professional boundaries

Gaps arising from issues related to professional boundaries were revealed across different professional groups and included limitations in knowledge and experience. Relationships and communication appeared to be affected. Knowledge gaps and lack of experience meant adverse outcomes were possible. For example, several doctors linked lack of knowledge in junior doctors as a risk, for example:

> "...Trying to get exposure to cover all aspects of neonatal care has been an ongoing issue. Learning about neonatal jaundice is not in any formal way mandated in training of general paediatricians." (neonatologist_C)

Midwives, including educators and those involved in policy development, also linked lack of adequate knowledge and clinical experience to poorer outcomes. One midwife summed up the situation this way:

> "…. [Neonatal jaundice] is probably not managed that well…. there is the potential for it to get missed….there is no surveillance strategy…. there is a deficit in the learning…. junior doctors lack experience; they are not good at putting the picture together; they may not even have seen the baby….midwives are generally not able to sign pathology slips….If the baby is starting to get jaundice within 24 hours – will call the paediatrician to look at the baby; we monitor – see how it goes...make sure feeding is happening frequently…..If early discharge –will home visit…….It might not be until the home visit that the midwife sees that

the baby is bright yellow.....Parents may think the baby has olive skin. Parents are not trained to look and assess.... Guidelines and protocols are only looked at when an issue comes up." (Midwife_C)

Professional boundaries rising from poor relationships and poor communication created potential gaps in care, particularly when role conflict existed. The most common example was differences between medical and midwifery paradigms, sometimes described as interventionist and non-interventionist approaches. The impact was evident in descriptions of assessment approaches. Midwives referred to using "intuition" or "instinct" as part of their professional assessment. In contrast, medical practitioners were likely to report erring on the side of caution for both testing and treating, "just in case". As one said:

"...we have to do that for fear of kernicterus. At a serum bilirubin level of 310, the baby receives treatment. It is not necessarily the right thing to do but don't want to miss pathological jaundice." (Paediatrician_C)

Tension between different professional relationships was evident in several interviews, such as between pathology personnel and clinical staff:

"There have been specific problems measuring bilirubin for a long time; trying to get it right; there is a combination of things; measurement, early discharge, lack of knowledge, lab measuring delay, haemolysed samples. Lab error is unlikely; if there is a mistake it is repeated." (Pathologist_C)

Professional boundaries affecting care were also reported within speciality groups in the same discipline, for example:

"There are conflicting views between the medical consultant and the paediatrician… for example in a baby with high SBR [serum bilirubin] the medical consultant will say put the baby under two lights; the paediatrician will visit later and say 'no just use one light'." (Midwife_A)

Professional boundaries affecting communication were most evident in accounts of absent feedback when neonatal jaundice was suspected, affecting confidence among less experienced professionals when potential cases were suspected.

> "...if you are seeing newborns babies all time, your skills are better, your assessment skills are better, when compared to midwives who only occasionally work with babies; you have a different perspective. There is a potential for over-reacting and under-reacting. I tend to overreact." (Educator, maternal and child health/midwife_C)

Blindness to possibility of adverse outcomes

Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in Australia, including one paediatrician, who despite reporting experience with many jaundiced infants, had had no direct experience of adverse outcomes, so felt one was unlikely. Similarly, one midwife explicitly questioned whether a kernicterus diagnosis was possible in Australia. Several others commented on the rarity of severe neonatal jaundice in Australia, also raising doubts about whether serious adverse outcomes occur.

Knowledge of adverse outcomes associated with neonatal jaundice was not considered important in Australian conditions according to some interviewees. When talking about their clinical education, the term "kernicterus" was recalled by some midwives as a "scary thing" or reportedly mentioned "in passing". Despite several comments about higher proportions of Asian women readmitted with jaundiced babies, only five participants (two paediatricians, a neonatologist, midwife and neonatal nursing educator), considered the needs of genetic diversity and ongoing population changes.

Very few participants recognised the increased risk for First Nation Australians. One paediatrician who worked in an area with a higher proportion of First Nation residents and those with Asian backgrounds, questioned the association with skin colour, commenting:

"One cannot make assumptions about ethnic heritage; there has been much exchange of genetic material over the years. Pigmentation is not fully developed in the first few weeks of life." (Paediatrician_A)

Competing professional development priorities

Almost all health professionals acknowledged difficulties in keeping abreast of research evidence; some felt individuals were responsible to keep up-to-date, but most relied on others to make research information available.

"I don't go looking for [information, literature] " (Midwife_B)

Participants who felt unable to keep up with research, also talked about other priorities, lack of access to resources or the size of the challenge:

"Keeping up to date with research is difficult. A significant number of midwives don't do it well. If outside the system, it is difficult, if not enrolled in University. How many journals can you subscribe to? It costs money. You rely on Google. You give up. Access is difficult. Enrolling in University costs money and you need time" (Midwifery educator/consultant_C)

Most participants agreed that neonatal jaundice was one of many conditions that health professionals need to know about. Several acknowledged lack of understanding of normal physiology or differences between physiological and pathological jaundice. Overall, professional development opportunities on neonatal jaundice care were limited.

Unintended consequences

Systemic issues within service delivery and organisations revealed unintended consequences, such as the absence of mechanisms to document adverse effects. Some participants pointed out that without such information measuring impact is difficult. Participants cognisant of potential consequences remarked:

"One may not know the outcome of severe neonatal jaundice for years. Hearing loss may be evident within hours." (Pathologist_D&F)

"Common reasons for readmission are G6PD, ABO incompatibility, dehydration, bruising. There is less awareness around these. The number of babies readmitted is not coded as separate. It is not easy to get this information." (Neonatologist_E)

Many interviewees commented on the potential cost of testing, which was commonly considered in terms of over-testing and over-treatment. One participant considered the prevention of severe neonatal jaundice attributed to ABO incompatibility and said:

"You would need to test every parent and child. Test fathers, test cord blood. Per baby it would be $150 extra assuming 200,000 babies born per year – there would not be much benefit." (Paediatrician_C)

In contrast, another participant felt it would be cheaper to test every baby "as then the health service cannot be sued….". Several doctors and a pathologist raised the potential costs associated with one missed case.

Early discharge of mothers and babies was commonly identified as a potential problem for neonatal jaundice identification. All participants working in hospital postnatal wards identified early discharge as a barrier to developing better clinical knowledge:

"There is a concern about early discharge. It is a problem in Australia. It seems greater [than in other countries]. Our women get kicked out. Monitoring is variable across Australia. What is the monitoring process?" (Neonatologist_C)

Issues arising from early discharge included variability in post-discharge care, where neonatal jaundice management was variously described as "haphazard" or dependent on "competing demands" with "no dedicated surveillance" measures in place. While one neonatologist described a robust community system, numerous others, including other neonatologists, did not concur:

"Need better way of streamlining taking serum bilirubin levels at home. Would need to report to the registrar. All midwives at home should perhaps carry a bilirubinometer. Institutions vary – each hospital will have its own policies. …. Need resources for daily home

visits for a minimum of three days until the maternal and child health nurse kicks in; need lactation support." (Neonatologist_C)

Contributing to uncertainty about patient care trajectories was growing reliance on a casualised workforce, particularly in midwifery, which was seen to affect skill and knowledge development:

"Midwives, we are reliant on them for recognising and assessing; they are a mixed bunch; quite a number do shifts in post-natal ward. They are semi-deskilling themselves. Not keeping up to date. They occasionally take a while to properly communicate regarding jaundiced cases." (Paediatrician_C)

Poor knowledge of neonatal jaundice among health professionals also affects communication with parents about the condition. Some participants pointed out that no specific information for parents existed while others were concerned not to overwhelm parents with more information than needed.

We know what should happen – but how?

The second major theme was the perception among participants that while they knew what was required to improve care, they were unsure how to achieve those changes.

Improvements in education and training

Almost all participants expressed needs for better education, particularly for midwives and junior doctors and parents. Several participants suggested that links between curriculum, guidelines and clinical practice were missing:

"There was a little bit of education around neonatal jaundice during medical training; not thorough; not much at all. It should be covered better especially for GP obstetricians. My general knowledge is not great about neonatal jaundice. There is a midwife educator….. maybe should have a bigger role. This may include keeping in touch with current research publications; to let us know what is out there." (GP/Obstetrician_C)

Guidelines were frequently portrayed as ineffective tools for evidence-based care. The development and update of clinical guidelines was described as time-consuming. Several participants reported

that guidelines were not included in their professional training and were considered difficult to navigate and not specific enough to be useful.

> "Guidelines. Don't use them, don't look at these." (Midwifery educator_C)

> "We need concrete guidelines around when to take SBR [serum bilirubin], for example if the jaundice is below the belly button, you need to do a blood test. Need to take way subjectivity." (Educator/maternal and child health coordinator/midwife_C)

Standardised policies and protocols

Most participants described policies and processes relating to neonatal jaundice management as variable and viewed as significant barriers to achieving necessary changes. Underpinning concerns were inconsistent or confusing language. Several participants pointed to examples of how different types of jaundice were described and assessed. For example, "clinical jaundice" was used to describe jaundice requiring a blood test and "jaundice" used when "severe jaundice" meant. Conflation created confusion—and, in the views of some participants—diminished the importance of severe bilirubin among clinicians.

While calls for consistency in neonatal jaundice management came from across discipline areas, all conceded that reaching agreement was difficult. Some health professionals felt there was already multidisciplinary collaboration in policy and guideline development, while others believed such collaboration to be missing. Challenges included a "them-and-us" mindset, including between tertiary centres and smaller services, and even siloed approaches within tertiary centres.

The wordiness of guidelines was frequently criticised. Poor accessibility exacerbated dissatisfaction. Participants using guideline websites found navigation difficult. The majority felt current guidelines needed to be reviewed, updated, or in some views, developed. Some called for more prescriptive guidelines "to rule out grey areas".

"Guidelines – they are not easy to find; website is not intuitive, guidelines are under "metabolic" (section). At 3am in the morning, when everyone is tired, (guidelines are) hard to find. On-line - so many guidelines. Use most recent but many are out of date." (Paediatrician_A)

Discussion

In looking at the experiences of Australian health professionals with neonatal jaundice management, challenges with implementing evidence-based care have been revealed. Several gaps in effective implementation were identified alongside feelings of inability to enact effective change. These issues are likely to apply beyond neonatal jaundice management to the wider use of evidence-based care.

Four of five contexts relevant to clinical practice guideline implementation identified in the meta-review exploring barriers and facilitators,(16) were evident in this study: the clinical guidelines themselves, the health system, the socio-political context and health professionals. This study also identified particular challenges for evidence-based care when adverse events are rare.

Consistent with the most frequently mentioned barrier to guideline implementation in the meta-review(16) were clinical guidelines themselves, particularly with lack of clarity. Other issues such as problems with credibility and day-to-day practice feasibility were also present and appear to be related to inconsistency, lack of standardisation, and unnecessary wordiness. Poor accessibility to guidelines exacerbated dissatisfaction and fuelled scepticism about guideline usefulness.

Barriers identified in the health system context in the meta-review, lack of time, resources, and specialised personnel(16) were also raised in this study. Two other health system developments were linked to possible unintended consequences for neonatal jaundice management. Early discharge practices were directly attributed to creating difficulties for timely diagnosis. Participants pointed out that in the context of early discharge greater need for parent awareness of neonatal jaundice exists. Predictors of discharge 'readiness' explored in a US study involving 185 mothers,

suggest that potential problems could be ameliorated by good pre-discharge education practices, although education depends on what, and how, nurses are able to teach mothers before leaving hospital.(32) Workforce casualisation was another health system issue identified as a potential barrier to good care for midwives in particular, reducing opportunities to acquire and reinforce neonatal jaundice knowledge.

The political and social context identified in the meta-review included barriers such as absent or poor leadership, teamwork difficulties; and lack of agreement between colleagues around guideline implementation.(16) In this study, issues of leadership and implementation agreement were also raised although interprofessional conflict was more frequently reported. Problems with interprofessional boundaries in health care can be found across the literature. For example, professional boundaries have impeded attempts to deliver best practice in unintended or unexpected ways. In Wales, an attempt to reduce unnecessary childbirth interventions by promoting midwife-led care using a clinical pathway found stricter boundary delineation actually reduced the scope of midwifery practice.(33) Whereas in Australia, inter-professional differences affected communication and information transfer in a study looking at child and family health services.(34) Problems with interprofessional boundaries and communication have consistently been highlighted in investigations into patient harm in maternity and neonatal services in England. (35-38)

Key to resolving professional conflicts is understanding that divergent perceptions do arise between disciplines, and even within the same discipline. This was evident in this study where the inclusion of several discipline groups found conflicting paradigms guiding care. This is not unique to Australia or to neonatal jaundice management. In a large Swedish university hospital study, existing power relations impeded effective professional teamwork.(39) Awareness of the interrelationships between professions, particularly when professional knowledge and work overlap, needs consideration in planning care and in developing guidelines. Interprofessional relationship issues, characterised by competition and conflict, seem central to professional identity.(40) They need

ongoing attention. Interdependent professions can experience constant conflict when continuous engagement related to expert labour and jurisdictional disputes exist. Resolution, when it does occur, tends to be temporary and followed by renewed disturbances.(40) Interprofessional collaboration and the need for synergizing professional roles has been the concern of numerous studies. (41-42) Contextual factors and the autonomous and collaborative aspects of professional roles need to be considered.

Gaps in neonatal jaundice knowledge were acknowledged in this study and in other studies and other countries. For example, in the USA, a cross-sectional study of paediatricians(43) found significant uncertainty in relation to identifying risk factors and using diagnostic approaches to manage neonatal jaundice. Congruent findings were also found in a root-cause analysis of 125 full-term infants with acute bilirubin encephalopathy voluntarily reported to the Pilot USA Kernicterus Registry (1992 to 2004), where the progression to hazardous bilirubin levels was attributed to the inability of multiple health professionals across multiple sites to identify at-risk infants or to manage severe hyperbilirubinemia in a timely way.(44)

An important finding of this study, unrelated to previous studies in this area, relates to particular challenges when adverse events are rare. Low case frequency may give clinicians false confidence that processes are working. The incidence of severe neonatal outcomes arising from extreme neonatal hyperbilirubinemia in Australia, when reported by clinicians, is around 10 per 100 000 live births.(6) While international comparisons are difficult due to definitional differences, including serum cut-off levels, gestational age ranges, and methods of data collection, a Swedish study that identified cases of kernicterus (bilirubin encephalopathy) through medical records, found almost half were most likely avoidable. These were attributed to failure to adhere to best practice, including untimely or no bilirubin screening, misinterpretation of bilirubin levels, and delayed or failure to initiate treatment.(45) That some health professionals in this study dismissed the possibility of severe adverse outcomes in Australia is concerning, particularly as lack of awareness of the

possibility of poor outcomes can be the most significant barrier to improving patient safety.(46) The absence of ongoing reporting of all adverse neonatal outcomes, including severe neonatal jaundice, appears to be critical. In the absence of adverse outcome data, there is little opportunity for health professionals to build knowledge or to make reasonable cost-benefit judgements.

Strengths and Limitations

Both strengths and limitations are present. Several health disciplines across geographical and work settings in Australia were involved, providing a broad range of perspectives. Limitations include the extended period for data collection and analysis, which were driven by practical constraints. The study was conducted over a staggered period, somewhat mirroring the process of guideline development. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.(17) The slow pace of analysis also gave time for reflection. The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable. The decision not to record interviews may be viewed by some as a limitation but also encouraged participation and all scripts were verified by interviewees. Interview scripts written directly after interviews have been shown to have similar quality to audio-recorded transcripts.(27) Despite its limitations, this paper presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.(47)

Conclusion

Multiple barriers to the provision of evidence-based care related to neonatal jaundice management are experienced by health care professionals in Australia. Clinical guidelines are not sufficient to support health professionals deliver evidence-based care in the complex contexts in which they work. Implementation strategies for evidence-based practice need to take account of health professionals' experiences and the challenges they face. Implementation strategies for neonatal jaundice management need to consider how to raise awareness of the importance of avoiding

severe adverse outcomes, despite their rarity, the consequences are devasting. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice is essential. Gaps in evidence-based practice arise even when clinical guidelines exist, and health professionals do not know how to address them.

Contributor statement

C.T. conceived the study design and collected all data. C.T. wrote the main manuscript text with support from D.H. All authors reviewed the manuscript.

Competing interests

The authors declare that they have no conflict of interest.

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Figure 1- Analysis of 41 interviews with health professionals: two major themes and explanatory sub-themes.

Data Availability Statements

All data relevant to the study is included within article or uploaded as supplementary information. De-identified interview scripts are available upon reasonable request from a controlled access repository. Deidentified interview scripts are available upon reasonable request from a controlled access repository (Figshare: https://figshare.com/s/8cd109d0a2b49ac8071c). Reuse is permitted when there is a published protocol or detailed plan for analysis.

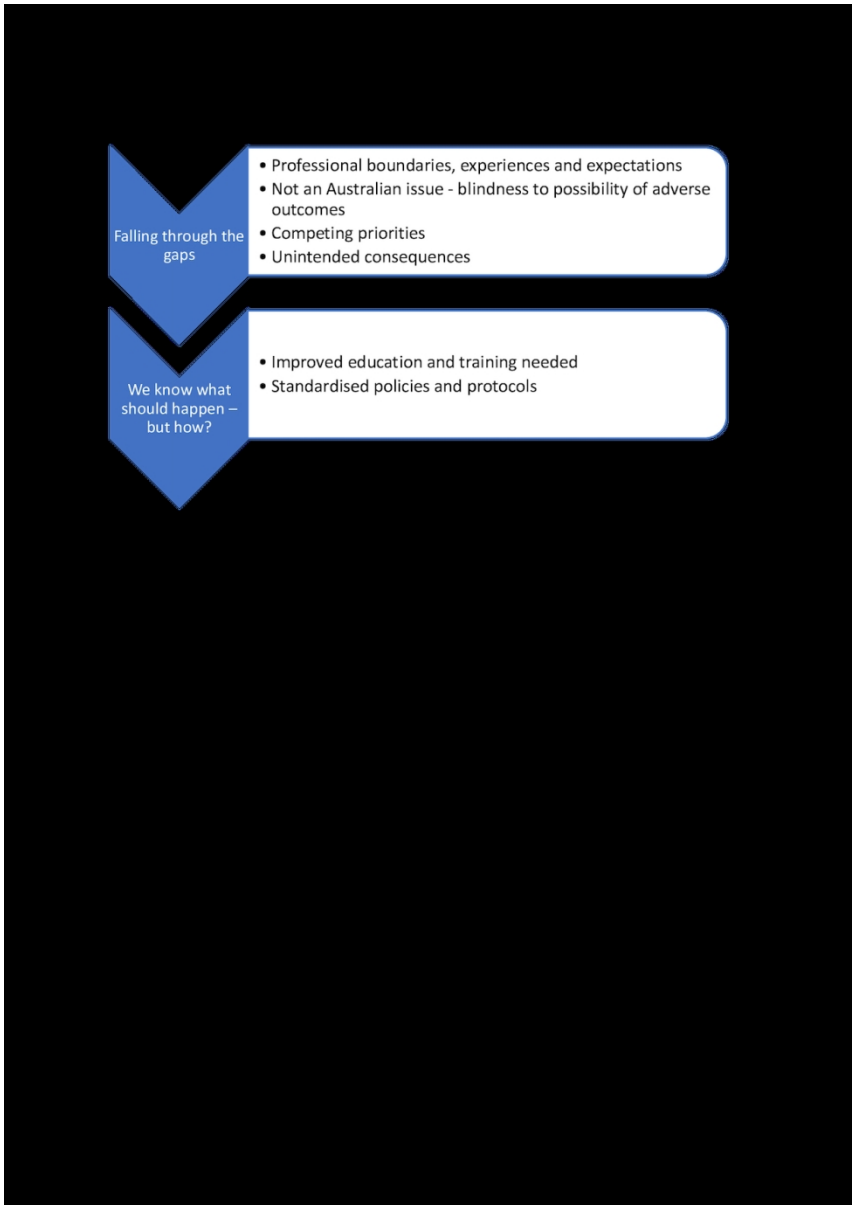

Figure 1 Themes and sub-themes: Analysis of 41 interviews

209x297mm (150 x 150 DPI)

Supplementary File: Interview/Discussion Guide

Theme List

a) general experience
b) how neonatal jaundice is managed
c) educational preparation
d) policy and guidelines
e) research and ongoing professional development, and
f) identified gaps.

Prompts

Questions were modified depending on relevance to the participant health professional category.

1. How long have you working as a (type will be specified)? Can you tell me a bit about yourself and what your work involves?

2. What has your general experience been in relation to neonatal jaundice – its recognition, assessment and management?

3. Do you think neonatal jaundice is well managed?

4. Does your organisation have a surveillance strategy for neonatal jaundice?

5. Approximately how many cases of newborn jaundice have you observed? Approximately how many of these required testing?

6. How is jaundice assessed? Can you outline the steps?

7. To what extent have you relied on visual estimation of jaundice?

8. When is a bilirubin test ordered?

9. How is bilirubin tested where you work? What technologies and processes are involved?

10. How do you interpret bilirubin levels? Above what level is treatment considered?

11. What is the highest level of bilirubin you have observed?

12. Have there ever been problems with the testing equipment? If so, can you recall what these problems entailed?

13. Are you aware of any jaundice management guidelines? What do you think about these guidelines? Do you use them? How are these guidelines developed and reviewed?

14. What training is provided to you, and by whom, in relation to neonatal jaundice?

15. Are you happy with the level of training and ongoing professional development offered to you in relation to neonatal jaundice?

16. How do you keep up to date in terms of the local, national and international literature relating to the management of neonatal jaundice?

17. Do you have any idea of the percentage of neonates readmitted for treatment of jaundice?

18. How confident are you about the risk factors for severe neonatal jaundice? Can you tell me what they are?

19. Do you know what the potential outcomes are if neonatal jaundice is unmonitored or untreated?

20. Over the last ten years or so, how have you adjusted your practices in relation to the management of neonatal jaundice? Consider technology advancements, early discharge policies, etc.

21. From your experience, are there any obstacles in the effective management of neonatal jaundice?

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