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a critical interpretive synthesis of the literature**

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DOCTOR OF PHILOSOPHY

# Rituals surrounding the care of the dying previabile baby in labour ward

*a critical interpretive synthesis of the literature*

Joan Elaine Cameron

2011

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## Evaluating professional guidelines for the care of dying pre-viable infants

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### Abstract

**Objective.** To identify, describe and evaluate published professional guidelines for the care of dying pre-viable babies.

**Design.** Systematic review and a search of databases including PubMed, MEDLINE and the Cochrane Library.

**Setting and sources.** Publicly available, English language guidelines for the care of dying pre-viable babies identified through a systematic literature search.

**Analysis.** Applying the Appraisal of Guidelines for Research and Evaluation (AGREE) collaboration instrument to six guidelines for the treatment of pre-viable babies.

**Results.** The analysis demonstrated that the process of guideline development was not carried out in line with best practice as recommended by the National Institute for Health and Clinical Excellence (2007). The lack of an evidence base for care was not indicated in the guidelines.

**Conclusions.** Current guidelines for the care of dying pre-viable babies appear to be based on description and opinion, rather than evidence. Future guideline developments for this group of vulnerable babies and their families should follow a more transparent and systematic process to enable health professionals to deliver effective care.

**Key words:** Dying pre-viable baby, guidelines, evaluation, AGREE evaluation tool, palliative care, evidence base

### Introduction and background

The legal age of viability in the UK is currently 24 completed weeks' gestation (Nuffield Council on Bioethics, 2006). Approximately 60% of infants born alive before 24 completed weeks' gestation will die in the delivery room and a further 30% will die soon afterwards in the neonatal intensive care unit (Costeloe et al, 2000; Vanhaesebrouck et al, 2004). The survivors are likely to experience severe morbidity, including chronic lung disease, visual defects and cerebral palsy (Marlow, 2004). The RCOG ethics committee discussing the ethics of prolonging life in the newborn states: 'Concerns about suffering might lead to a positive argument for resuscitation limits ... as many babies ... may be suffering from multiple, repetitive and invasive neonatal treatments' (RCOG, 2005: 3).

The UK has no definitive limits in relation to the initiation of resuscitation and treatment of very preterm infants. However, the principle of 'best interests' holds that any treatment or intervention that might produce suffering must have commensurate benefits for the infant (Nuffield Council on Bioethics, 2006). In relation to pre-viable infants, the potential outcomes must be weighed against the pain and suffering caused by the necessary interventions. In many cases, the outcome for the infant will be death or severe impairment. In these instances, it is permissible for life-sustaining treatment, such as resuscitation, to be withheld. The Royal College of Paediatrics and Child Health (RCPCH) guidelines advise: 'Withdrawal of life-sustaining treatment in appropriate circumstances is not seen by the courts as active killing, nor as a breach of the right to life under Article 2 of the European Convention of Human Rights' (RCPCH, 2004: 21).

Where resuscitation and active treatment are withheld, the report of the Nuffield Council on Bioethics (2006) recommends

that palliative care should be offered. The concept of palliative care includes meeting physical needs for warmth, relief of pain, hydration and nutrition, as well as providing support to meet the psychological, spiritual and social needs of the patient and the family (Saunders, 1996).

Palliative care is a relatively new concept in neonatal care. Research into neonatal palliative care so far has focused on describing the nature of the care delivered (Moro et al, 2006; Kain, 2006; Ramer-Chrasek, 2005), barriers to its provision (Kain, 2006) and tabulating the type of care given such as the involvement of parents, withholding or withdrawal of care or the provision of pain relief, rather than the effectiveness of care (Moro et al, 2006). Research into the provision of palliative care for neonates focuses on babies who have been admitted to neonatal intensive care units, rather than pre-viable babies who are being cared for in labour wards (Ramer-Chrasek, 2005; Kain, 2006; Moro et al, 2006).

The needs of dying pre-viable babies being cared for on labour wards are not explicitly addressed. Pre-viable babies who die on labour wards will be cared for by midwives or neonatal nurses without specialist expertise in caring for sick neonates. They are unlikely to be monitored so assessment of physiological parameters to determine the need for palliative care interventions, such as pain relief or oxygen is difficult. Pre-viable infants are also unlikely to have intravenous access established in the labour so the provision of pain relief and nutrition is difficult to accomplish.

Increasingly, guidelines have been seen as a means of providing health professionals with evidence-based health care for dealing with specific clinical situations (Woolf et al, 1999). Guidelines have been developed to inform the care of dying



**Table 1. Total number of guidelines retrieved, showing those included and excluded from each source**

Source	Total number papers retrieved	Papers identified as potentially eligible	Number excluded after scrutiny	Guidelines meeting all inclusion criteria and included in review
PubMed	25	4	3	1
MEDLINE	17	2	2	0
CINAHL	328	4	4	0
Science Direct	128	0	0	0
SCOPUS	0	0	0	0
MIDIRS	250	4	4	0
Professional organisations	16	15	11	4
National Library of Guidelines	3	1	1	0
National Guideline Clearinghouse	1	1	1	0
Scottish Intercollegiate Guidelines Network	0	0	0	0
NICE	0	0	0	0
Online discussion groups	1	1	0	1

pre-viable babies. The purpose of this review, therefore, is to identify, explicate and evaluate published guidelines for care for the dying pre-viable infant to explore the nature of the evidence cited and assess their fitness for purpose.

#### **Inclusion and exclusion criteria**

For the purpose of the review, guidelines were defined as a statement by or for health professionals that outlined recommendations for care of dying pre-viable infants. This definition enabled the inclusion of policies, protocols and practice standards for the care of dying infants born at 24 weeks' gestation or less. Recommendations for care might include explicit reference to tasks such as providing nutrition or pain relief, or they could include generic terms such as 'comfort care' (NMC, 2007) 'compassionate care' (MacDonald et al, 2002) or 'palliative care' (Nuffield Council on Bioethics, 2006). The guidelines also had to be in the public domain so that they were accessible to practitioners.

Previous research investigating parental participation in ethical decision-making and visiting policies in Europe and Asia demonstrated that there were significant variations in practice between English-speaking and non-English-speaking countries (McHaffie et al, 1999; Partridge et al, 2005). English-speaking countries tended to share a common philosophy in respect of ethical frameworks and parental participation in care. For those reasons, it was decided to include only documents produced in English and in-

tended for use in North America, Australia, New Zealand and the UK. It was also believed that translating guidelines from other languages into English for comparison could mean that subtle nuances or taken-for-granted meanings might be lost or misinterpreted.

The EPICure study in 2000, a population-based study of survival and later health status in extremely premature infants, provided robust information about survival rates of babies born at the threshold of viability and this may have had an impact on the development of guidelines and clinical practice (Costeloe et al, 2000). It was therefore decided to limit the search to the period between 2000 and 2007. Guidelines developed or published before that date, but identified as still being current and informing clinical practice would be included in the review.

Guidelines that focused exclusively on the ethical or clinical decision-making process about the need for resuscitation and care were excluded from the review. Guidelines that referred exclusively to the withdrawal of care from infants without making specific reference to pre-viable infants were also excluded, as the intended focus of the review was the care of infants of less than 24 weeks' gestation. For example, the report of Nuffield Council on Bioethics (2006) was excluded from the review as it made general recommendations about the need for professionals to agree guidelines for palliative care of pre-viable infants, while the guidelines produced by the Stillbirth and Neonatal Death Society (SANDS) were included because they made specific reference to forms of care that health professionals should deliver to pre-viable babies who were not to be resuscitated (SANDS, 2007).

#### **Search strategy**

Assigning key words for the search was problematic as there is no agreed terminology to describe babies of less than 24 weeks' gestation. The following terms have all been used to refer to babies born at less than 24 weeks' gestation: 'very preterm', 'extremely low birthweight' (Marlow, 2004); 'threshold of viability', 'extremely preterm' (MacDonald et al, 2002); 'non viable' (Macfarlane et al, 2003); 'border of viability', 'perivable' (Higgins et al, 2005); 'pre-viable' (British Association of Perinatal Medicine (BAPM), 2000). It was decided to use all the terms identified to search relevant databases. The terms were combined with 'guidelines' using Boolean connectors or by using search limits, where available. Some databases also permitted the use of further limits. Where additional limits were allowed, those used included 'English language', 'human', and 'title and abstract'.

The following databases were searched: PubMed, MEDLINE, CINAHL, Science Direct, SCOPUS and MIDIRS. The websites of professional organisations related to midwifery, obstetric and neonatal nursing, paediatrics and gynaecology from North America, New Zealand, Australia and the UK were also searched as were the following guideline collections: National Library of Guidelines, Scottish Intercollegiate Guidelines Network, National Institute for Health and Clinical Excellence (NICE) and the National Guideline Clearinghouse. Midwifery

**Table 2. Appraisal of Guidelines for Research and Evaluation Domains (AGREE) instrument (AGREE, 2001), showing those included and excluded from each source**

Domain	Questions
Scope and purpose	The overall objectives of the guidelines are specifically described. The clinical questions covered by the guidelines are specifically described. The patients to whom the guideline is meant to apply are specifically described.
Stakeholder involvement	The guideline development group includes individuals from all the relevant professional groups. The patients views and preferences have been sought. The target users of the guidelines are clearly defined. The guideline has been piloted among target users.
Rigour of development	Systematic methods were used to search for evidence. The criteria for selecting the evidence are clearly described. The methods used for formulating the recommendations are clearly described. The health benefits, side-effects and risks have been considered in formulating the recommendations. There is an explicit link between the recommendations and the supporting evidence. The guideline has been externally reviewed by experts prior to its publication. A procedure for updating the guideline is provided.
Clarity and presentation	The recommendations are specific and unambiguous. The different options for management of the condition are clearly presented. Key recommendations are easily identifiable. The guideline is supported with tools for application.
Applicability	The potential organisational barriers in applying the recommendations have been discussed. The potential cost implications of applying the recommendations have been considered. The guideline presents key review criteria for monitoring and/or audit purposes.
Editorial independence	The guideline is independent from the funding body.

online discussion groups and a perinatal network were contacted to ensure that guidelines not appearing in national collections or in the public domain were included.

Titles and abstracts were scrutinised. Where these indicated that the paper met the inclusion criteria, or if the title or abstract was ambiguous, the full guideline was obtained. The websites of professional organisations had search facilities, but these were not specific enough to enable the identification of guidelines referring to the care of dying previsible babies. This meant that each website was hand-searched, with all potentially relevant documents being downloaded and scrutinised. Reference lists (where available) were also examined for relevant guidelines. Guidelines that were excluded from the review were checked by three reviewers to ensure rigour in the final selection of guidelines for the review.

Table 1 shows the total number of guidelines retrieved, exclusions and inclusions. The majority of papers excluded from the study focused on ethical decision-making in relation to the provi-

sion of resuscitation and ongoing support in the case of previsible birth; and those that focused on withdrawal of care without making specific reference to the care of previsible babies. Some guidelines were retrieved from multiple sources. Where this occurred, the guideline was attributed to the first source and then excluded from later searches.

A total of six guidelines were identified (see Table 1). Of the six guidelines retrieved, four were from the UK (SANDS, 2007; Thames Regional Perinatal Group, 2000; BAPM, 2000; NMC, 2007). The remaining two guidelines were from North America (MacDonald et al, 2002; Canadian Paediatric Society, 1994). No guidelines from Australia were identified. Five guidelines were available on the internet. The guidelines for professionals developed by SANDS were available to buy at a cost of £16.99. It was decided by the review group that the guidelines still met the criteria of being in the public domain and so they were included.

#### Analysis

To undertake the critical analysis of the guidelines, the research team used the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (AGREE Collaboration, 2001). This tool has been developed and validated for the evaluation of clinical guidelines (AGREE Collaboration Writing Group, 2003). The AGREE instrument provides a structure to assess the quality of the process of guideline development and the quality of the recommendations. However, it is unable to assess the impact on outcomes.

The AGREE instrument consists of 23 questions organised into six domains (see Table 2). The domains address different aspects of guideline quality (AGREE Collaboration, 2001). Each item has a four-point scale that ranges from strongly agree to strongly disagree, with two mid-point scores. Each item also has accompanying explanatory notes to enable the appraiser to clarify the meaning behind the questions. It is recommended that each guideline is appraised by a minimum of two people using the instrument. For maximum reliability, four appraisers are recommended. For this evaluation, four appraisers participated.

Three appraisers were associated with a doctoral project evaluating ritual processes in the care provision for dying previsible babies. Of these three, one is a midwifery academic with experience of caring for neonates; one is a professor of family health with a special interest in child protection; and the third is an anthropologist who also trained as a nurse. The fourth appraiser was a nurse academic with expertise in neonatal intensive care.

Before undertaking the analysis of the guidelines, the AGREE tool was piloted with a group of students undertaking doctoral programmes of research in the College of Medicine, Dentistry and Nursing at the School of Nursing and Midwifery. As a result of carrying out the pilot analysis, it was established that only the part of the guideline relating to the care of the dying previsible

Table 3. Application of the AGREE instrument to guidelines\*

Domain question	SANDS	Thames Regional Perinatal Group	British Association of Perinatal Medicine	American Academy of Pediatrics	Canadian Paediatric Society	NMC
Scope and purpose	47.2%	50%	38.8%	61%	55%	38.8%
Stakeholder involvement	68.75%	22.9%	12.5%	16.6%	22.9%	22.9%
Rigour of development	26.1%	10.7%	1.19%	21.4%	20.2%	30.9%
Clarity and presentation	39.5%	2.08%	2.08%	14.58%	10.4%	18.75%
Applicability	19.45%	8.33%	0%	0%	5.5%	0%
Editorial independence	12.5%	12.5%	12.5%	12.5%	20.8%	25%

\*A domain score of less than 40% was obtained where at least two appraisers awarded scores of 2 or less (disagree or strongly disagree) for each question in the domain. A score of 50% or more was obtained where at least two appraisers awarded scores of 3 or more (agree or strongly agree) to each question in the domain

baby should be evaluated. Most of the guidelines had embedded this information in the wider framework addressing decision-making and care of babies who were to be resuscitated. From the pilot, it was clear that there were potentially significant differences in the way the different outcomes were considered and analysing the guideline as a whole would lead to skewing of the results related to the care of dying pre-viable babies.

For example, several guidelines addressed the needs of pre-viable infants who were to be resuscitated and provided recommendations based on randomised controlled trials (MacDonald et al, 2002; Canadian Paediatric Society, 1994). Where there was a lack of evidence in relation to specific approaches to care, this ambiguity was clearly acknowledged (MacDonald et al, 2002; Canadian Paediatric Society, 1994). The section on caring for dying pre-viable babies, however, would not acknowledge the evidence base (or lack of it). The reviewers decided that it was important that the section on caring for dying pre-viable babies should stand on its own in order to be reviewed in each of the guidelines.

### Findings

To facilitate evaluation and comparison of the guidelines, the findings are presented using the domains specified in the AGREE instrument. Table 3 shows the percentage scores for each domain for the guidelines. The percentage scores are obtained using the formula advised by the AGREE Collaborative Group to obtain a standardised domain score. To evaluate a guideline using the instrument, the score for each domain is added up and scored as a percentage. This is not particularly helpful to the reader in understanding the relationship between the percentage scores and the way in which they were scored by the individual appraisers. In this study, a domain score of less than 40% was obtained where at least two appraisers awarded scores of two or less (disagree or strongly disagree) for each question in the domain. A score of 50% or more was obtained where at least two appraisers awarded scores of three or more (agree or strongly agree) to each question in the domain.

The AGREE Collaboration suggests that domain scores should not be aggregated and that it is impossible to set scores against

a threshold score for 'good' or 'bad' guidelines (AGREE Collaboration, 2001). Instead, it is recommended that the appraiser makes an overall judgement about the quality of the guideline at the end of the assessment.

### Scope and purpose

NICE recommends that guidelines should have specific aims and objectives and the expected health benefits or outcomes should be identified (NICE, 2007). The population for whom the guideline is intended should also be specified to enhance the use of the guideline (NICE, 2007). This

information assists health professionals when searching for relevant guidelines.

Five guidelines indicated that the pre-viable baby was the focus of the guideline (MacDonald et al, 2002; NMC, 2007; Thames Regional Perinatal Group, 2006; BAPM, 1994; SANDS, 2007). One guideline referred to the woman as the focus of care (Canadian Paediatric Society, 1994). The lack of focus in the guideline title could mislead professionals when searching for information.

### Stakeholder involvement

In developing a guideline for clinical practice, it is essential that those involved have the relevant expertise (Woolf et al, 1999). The guideline development group should also reflect the range of disciplines using it. In evidence-based care, the experiences and expectations of healthcare consumers should be taken into account when developing the guidelines and the process should be included in the final guideline (van Wersch and Eccles, 2001; NICE, 2008). It is recommended that the guideline should make explicit reference to the target users. If the target audience is not specified in the guideline, then it is possible that potential users may not be aware of the relevance of the guideline to their practice. The guideline should be piloted or tested with relevant user-groups as part of the development process and this should be recorded in the published guideline (AGREE Collaboration, 2001).

Three guidelines indicated that they had been prepared on behalf of an organisation or committee, but no further information was given about the individuals who participated in the development process (BAPM, 2000; NMC, 2007; Thames Regional Perinatal Group, 2000). Three guidelines gave details of professional employment details or professional qualifications (MacDonald et al, 2002; Canadian Paediatric Society, 1994; SANDS, 2007). One guideline included details of professionals and parents who had been involved in the guideline development (SANDS, 2007). While this guideline did indicate that parent experience had informed the development of the guideline, there was no information about the representativeness of the group and how the parents had been recruited.

Two guidelines provided explicit information about the

nature of the guideline and the target audience (Canadian Paediatric Society, 1994; MacDonald et al, 2002). Midwives and nurses are likely to be the main providers of care to the dying previsible baby. One guideline mentioned this group by name as target users (NMC, 2007). Generic terms such as 'clinicians' and 'other members of the healthcare team' were used by guidelines (Thames Regional Perinatal Group, 2000; MacDonald et al, 2002; Canadian Paediatric Society, 1994). One guideline provided no information about the specific target group for the guideline, but did refer to 'obstetricians, paediatricians, midwives, nurses and other supporting professionals' in the text (BAPM, 2000).

#### *Rigour of development*

Guidelines should be based on the best available evidence to enable practitioners to deliver care that is safe and effective. A guideline can only be as good as the evidence that informs its development. For that reason, the process of gathering and analysing the evidence and formulating the recommendations should be included in the guidelines. It is also considered good practice to submit guidelines to peer review before publication. The AGREE collaboration suggests that this should include people with appropriate professional and methodological expertise (AGREE Collaboration, 2001). Some guidelines may be reviewed by consumer representatives at this stage in their development. Since guidelines need to be informed by current evidence in order to be effective, it is considered to be good practice to include information about the updating process or including a review date in the guidelines (AGREE Collaboration, 2001).

None of the guidelines provided information about search strategies or inclusion and exclusion criteria. One guideline was unsupported by any references (BAPM, 2000). This guideline, however, was cited as 'evidence' by another guideline (NMC, 2007). It was not clear how the references to support the recommendations had been selected in the remaining guidelines. An explicit link between the recommendations and the supporting references was missing in all of the guidelines. None of the guidelines provided any critique of the cited evidence relating to the care of dying previsible babies or an indication of the quality of the evidence.

One guideline stated that external reviewers had been consulted and listed them in the guideline; however, no information was given as to the appraisal process (SANDS, 2007). One guideline was in the process of being reviewed (Canadian Paediatric Society, 1994). Another guideline indicated a review date (MacDonald et al, 2002). None of the remaining guidelines provided information about updating procedures.

Guidelines and recommendations usually come with an assessment of health benefits and risks, and balance these against the potential costs. The guideline produced by SANDS (2007) did make explicit the potential health benefits to society in ensuring the wellbeing and recovery of parents after the death of a previsible baby. However, the potential risks associated with the approach – the distress parents might feel at holding their baby when treatment was futile was not addressed. The potential costs of having to provide skilled support over a period of time to enable parents to interact with their dying baby was not addressed in any of the guidelines.

#### *Clarity and presentation*

This domain considers the way in which the options for care are presented and the dissemination and implementation strategy. It is suggested that the recommendations should be stated clearly and be easy to find. The guidelines should be precise about specific management approaches and determined by the body of evidence. If there is uncertainty about management then this should be reflected in the guideline (AGREE Collaboration, 2001). This domain also covers the dissemination and implementation strategy for the guidelines.

In the previous section, it was shown that the evidence base for the guidelines was poor. This made it difficult for the guidelines to be specific about the potential ways of managing care. The way in which care was described was vague and unlikely to be helpful to practitioners, for example, 'the use of opiates to provide a comfortable and dignified death may be entirely appropriate' (Thames Regional Perinatal Group, 2000). The guideline does not give any indication of how the need for opiates would be assessed, the dose and the possible routes of administration.

The recommendations for the care of the dying previsible baby were embedded in guidelines and were difficult to isolate (NMC, 2007; Thames Regional Perinatal Group, 2000; MacDonald et al, 2002; BAPM, 2000; Canadian Paediatric Society, 1994). One guideline had an identified chapter on late pregnancy loss and the care of the dying previsible baby was given a heading that enabled it to be isolated from other information in the chapter (SANDS, 2007).

Two guidelines had been published in journals read by a range of professionals (MacDonald et al, 2002; Canadian Paediatric Society, 1994). One guideline was distributed to key users (NMC, 2007). The remaining guidelines were available on a specialist website (Thames Regional Perinatal Group, 2000; BAPM, 2000). Only one guideline came with clear recommendations and suggestions for dissemination (SANDS, 2007).

#### *Applicability*

Applying the guideline recommendations may require additional resources or changes in practice. This domain assesses the extent to which the barriers to implementation have been addressed and how adherence to the recommendations can be assessed. This was missing from five guidelines. One guideline identified the need for staff training to implement the recommendations and criteria for review (SANDS, 2007). None of the guidelines discussed possible audit or review criteria to assess how the guideline for the care of the dying previsible baby was being used in practice.

#### *Editorial independence*

This domain refers to the need to make explicit the relationship between funders and the guideline development process. It also relates to potential conflicts of interests experienced by members of the development group. The AGREE evaluation tool recommends that there should be an explicit statement relating to potential conflicts of interest (AGREE Collaboration, 2001).

None of the guidelines had explicit statements relating to the interests of the guideline developers or funding. One guideline was developed by a charity who then offered it for sale (SANDS, 2007). It was recognised by the reviewers that the



current focus on perinatal loss came about because of the work carried out by consumer groups and their prominent use of their logo could be regarded as an explicit statement about their 'interest' in the guidelines.

#### *Overall assessment of guidelines*

The AGREE evaluation tool suggests that there should be an overall assessment of the quality of the guideline based on scores achieved for each of the domains and the judgement of the appraiser (AGREE Collaboration, 2001). Four options are available: 'strongly recommend', 'recommend with provisos or alterations', 'would not recommend' and 'unsure'.

The overall assessment for all six of the guidelines from each reviewer was 'would not recommend'. The main reason expressed for this judgement was the lack of rigour in the development of the guidelines that then impacted on the validity of the recommendations for care.

#### **Discussion**

The search strategy used for this review was able to detect current guidelines for the care of the dying pre-viable baby produced in the UK and North America. While there has been extensive debate around the ethics of resuscitation policies for pre-viable babies and outcomes of care, very little work has been undertaken to assess the quality of the guidelines for care when resuscitation is withheld (Boyle et al, 2004; Lucey et al, 2004; Janvier and Barrington, 2005).

The evidence base for guidelines is considered to be crucial in determining the validity of the guideline and its credibility for use by health professionals and consumers. Guidelines relating to other aspects of neonatal care such as resuscitation, and treatment modalities, such as neonatal surfactant therapy, follow the agreed convention of listing evidence and assessing it according to hierarchies of evidence (Penney and Cameron, 2004; Canadian Paediatric Society, 2005). However, the guidelines relating to the care of the dying pre-viable baby were descriptive with no direct link between the recommendations and evidence. In particular, the lack of an evidence base to support the recommendations was not acknowledged. The fact that an evidence base to support care is missing could be an important starting point for further research.

Providing palliative care is a complex activity. It requires a multidisciplinary team that includes specialist nurses and doctors, counsellors and often voluntary organisations, such as hospices (Ramer-Chrastek, 2005). The situation in relation to palliative care provision in pre-viable babies is more problematic. The baby may live from a few minutes to a few hours. The issue of identifying and relieving pain in the preterm infant is difficult, as the infant is unable to vocalise and immature muscle activity reduces physical responses to pain and discomfort. Neonatal assessment scales are available, but they require intensive training to use and their reliability in assessing the needs of dying pre-viable infants has not been tested (Westrup, 2007).

Guidelines and algorithms are designed to assist practitioners in decision-making. Examples of these include resuscitation algorithms (Resuscitation Council UK, 2005) and guidelines for decision-making around the mode of birth after a previous caesarean section (Montgomery et al, 2007). However, decision-making

around providing care for dying pre-viable infants can be fraught with emotionally difficult choices as staff try to achieve the ideal of creating a 'good death' for the infant and lasting memories for the parents. It may be difficult for guidelines that adopt a linear format to portray the complicated processes that health professionals must negotiate in order to provide effective care.

Caring for dying pre-viable babies is a difficult area to research. There are ethical issues around recruitment of parents and babies at a critical time, where there may be limited opportunity for the parents to reflect on their involvement in the study. Parents may feel strongly about certain aspects of care such as holding or dressing the baby so a trial-based approach would be inappropriate (Rådestad et al, 2008). Guidelines should make explicit the lack of evidence base for their recommendations. It enables staff to exercise caution when implementing the guidelines and may help stimulate further research into areas such as pain relief and parental support.

The AGREE evaluation instrument is a relatively new tool by which to assess guideline quality. Its use requires practice both in terms of familiarisation with the domain criteria and its application to guidelines to ensure consistency of use between reviewers. Although the tool was used for a very specific set of guidelines, the questions posed by the tool were of a generic nature and could be applied to almost any guideline. However, it is important at the outset to agree on certain parameters, for example, how stakeholders are defined. Rigorous pre-application briefings and piloting before using the tool might enhance the reliability of it. Alternatively, a consensus-based approach to its application could be used.

The application of the tool does not take into account the range of scores between the appraisers, but combines all the scores to obtain an 'aggregate' score. The method of scoring does not allow for 'deviations' to be calculated and this is a potential weakness of it. In this particular assessment where there were low scoring domains, there was good agreement. However, there were variations between assessors in the domains that achieved higher scores. The reason for this was unclear and requires further investigation to explore different understandings of the application of the AGREE tool.

Having assessed six guidelines using the AGREE tool, the main advantages of it appear to lie in the provision of specific criteria for the review and a scoring system that enabled a value to be placed on the individual domains by reviewers. This makes it possible for the domains to be compared across several guidelines and it also enables 'weak' or 'strong' areas of the guideline to be identified readily. The value of the percentage scoring system is less obvious and the authors would recommend that further work is done to evaluate the reliability of the numerical score against a qualitative score, for example, 'poor' or 'good'.

#### **Conclusion**

The guidelines included in this review were available in the public domain to inform the care given to dying pre-viable babies. The review cannot determine if the care actually delivered in practice follows the recommendations. What has been established is that the process for developing the guidelines for dying pre-viable babies lacks a systematic approach and appears to be based on description and opinion, rather than evidence.



Future guideline development should be based on the principles proposed by NICE (2007) as this embraces the concept of transparency and rigour. The use of the approach adopted by NICE could help identify where evidence currently exists and

could direct future research into providing care for this group of vulnerable babies and their families. The use of the AGREE instrument requires further work to explore its reliability and validity as a tool to evaluate guidelines.

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