



Birchley, G., & Cejer, B. (2013). Nurses as withdrawers of life sustaining treatment in paediatric intensive care. *Nursing in Critical Care*, 18(1), 43-51. 10.1111/j.1478-5153.2012.00532.x

Peer reviewed version

Link to published version (if available):
[10.1111/j.1478-5153.2012.00532.x](http://dx.doi.org/10.1111/j.1478-5153.2012.00532.x)

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Nurses as Withdrawers of Life Sustaining Treatment in Paediatric Intensive Care

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This is a prepublication draft that received only minor edits before publication. If citing please use the following information to reference the final published version:

Birchley G, Cejer B., Nurses as withdrawers of life sustaining treatment in paediatric intensive care. Nurs Crit Care. 2013 Jan-Feb;18(1):43-51. doi: 10.1111/j.1478-5153.2012.00532.x.

Abstract

Background: Withdrawal of life saving medical treatment is a common modality of death within United Kingdom Paediatric Intensive Care Units (PICU). The majority of treatment withdrawals are carried out by medical staff, usually the consultant in charge of the child's care.

Aim: To assess current practice of experienced PICU nurses performing the key tasks in treatment withdrawal once the decision has been made, and its legal implications.

Design and Method: The study was divided into three chronologically successive phases. In Phase 1 a twelve item paper survey was circulated to nursing staff on a UK PICU. In Phase 2 a three item survey regarding current practice was sent to nurse managers on 22 UK PICUs. In phase 3 analysis of legal issues related to nurses withdrawing treatment was undertaken.

Results: Poor response rates to both surveys limited their value, however they may stimulate discussion of the issue within nursing. Phase 1 received 15/100 (15%) responses; open ended questions highlighted practitioner concerns. 8/22 (36%) responses for phase 2 showed no consistent approach to the issue nationally. Legal analysis indicated the law was untested in this area and nurses would be advised to withdraw treatment only if following a documented medical plan. Risks of legal and regulatory action could be reduced by formulating clear guidelines.

Conclusion: PICU nurses could potentially enact withdrawal, but discussion is needed to resolve uncertainties.

Relevance to Clinical Practice: National Guidelines from within the PICU community could assist nurses participating in treatment withdrawal.

Keywords: Withholding/Withdrawing Treatment, Paediatric Intensive Care, Intensive Care Nursing, Law, Ethical Issues in Nursing, Practice Development

Introduction

In critically ill patients where there is no hope of recovery and treatment has been agreed by key parties to be futile, treatment will be discontinued in what is termed in the UK *withdrawal of life sustaining treatment*. This involves removing the endotracheal tube, stopping artificial ventilation, vasoactive medication and other organ support such as haemofiltration. Although exact figures are unknown, the withdrawal of life sustaining treatment in paediatric intensive care unit (PICU) environments is recognised as a major cause of mortality (Sands et al., 2009). Robust guidance on when life sustaining treatment can legally be withdrawn exists (Royal College of Paediatrics and Child Health, 2004) but guidance on how to withdraw treatment is limited. Care pathways and standards produced to guide professionals in terminal extubations of children is comprehensive, yet is not specific about who should remove the endotracheal tube (ACT, 2011; PICS 2002). A literature search produced no studies on the subject. Anecdotal evidence indicates that on rare occasions where treatment withdrawal is planned but no doctor is available nurses may take the lead role. It is the purpose of this paper to inform and stimulate debate of this practice.

To assess the current practice around nurses initiating treatment withdrawal among PICU patients, a three phase approach was developed to get a sense of the current situation. Surveys were undertaken to gauge local and national practice. Subsequently a legal analysis was undertaken to assess the standing of this practice and inform future policy development. In the event the response to the surveys was poor, however the legal research uncovered important dichotomies between legal and professional standards that have a bearing on future practice. As the surveys provide evidence of a hitherto unexplored area of practice, they have been included here despite acknowledged methodological weaknesses as they may provide a foundation for future research.

Literature Search

Although anecdotally it appears that nurses may sometimes withdraw treatment once this decision has been agreed between parents and clinicians, for instance when the family is ready to “say goodbye” but no doctor is available, the literature is silent on the practice. A literature search with the keywords NURSE, WITHDRAWAL, END OF LIFE, LIFE SUSTAINING, LIFE SUPPORT performed in 2010 on the Ovid and Westlaw databases produced no suitable results once the summaries of returned papers and legal cases were examined. Because of the paucity of returns no further numerical data relating to the searches was retained. Additional advice was sought by emailing the Nursing and Midwifery Council, who were unable to provide details of any policy regarding nurses withdrawing treatment. Academic advice on legal sources identified several parallel cases that might be a starting point for legal research.

To gain a practice perspective a survey of practice was conceived to explore anecdotal reports of nurses as withdrawers of life sustaining treatment. Meanwhile, further legal research would attempt to pinpoint the legal position. Once these investigations were concluded the aim was to offer guidelines to practitioners.

A Local study

A survey of nursing staff at one regional PICU was conducted in February 2010 to explore current practice. The survey, along with a letter outlining the project aims and explaining all data would be confidential and anonymous, was placed in the common room where staff have refreshments. A total of 100 nursing staff were eligible to participate and there were no exclusion criteria. The survey (Appendix 1) consisted of twelve questions was devised in consultation with the senior nurses and doctors on the PICU, and tested on nurses with critical care experience. These surveys asked for both quantitative and qualitative information about the practicalities of treatment withdrawal from children by nurses. Guidance from the national research ethics service (NPSA, 2010) indicated that because the surveys sought to define the current standards of care, they were service evaluations of existing practice and no ethical review was needed. The relevant hospital committee was not therefore contacted at the time, although with hindsight it is conceded they may have offered advice in the survey formulation. The survey did however follow trust guidance on data protection and confidentiality, and prior to publication retrospective registration of the study was granted by the Trust’s research and innovation department. The response rate was 15/100 (15%). Nine respondents had cared for children during the withdrawal process on more than five occasions. The poor response rate may have been due to the relative inexperience of withdrawal

among the nurse population at that time (a quarter had worked in PICU for less than two years). Additionally a number of clinical research projects were also running concurrently and this may have resulted in research fatigue among potential participants (Gerrish and Lacey 2006); It is acknowledged the timing of the survey may demonstrate naivety on the part of the researchers. The data is nevertheless interesting. Thirteen respondents had experience of withdrawal and all reported the actual withdrawal was conducted by a doctor. In these there were two reports the nurse removing the endotracheal tube, and eight reports of stopping inotropic infusions once a decision to withdraw had been agreed. The qualitative answers contained a variety of concerns. Respondents clearly felt that the needs of families were central to issues around withdrawal of treatment, particularly who should withdraw and when withdrawal should take place, and that these needs might justify nurses taking a lead role in withdrawal. There was also concern about the legal position of nurses initiating withdrawal.

Scoping national practice

To gain an impression of the national standard a short 3-item survey was developed and agreed by senior nurses (Appendix 2). This was delivered electronically by our senior nurse to 22 PICU nurse manager forum members across England, Wales, Northern Ireland and Scotland. The questions covered current withdrawal practice within their unit, the role of nurses during the withdrawal process and the availability of unit guidelines or policies to support nursing staff in implementing withdrawal once a decision to discontinue care had been made.

Responses were received from 8/22 (36%) of the PICUs. Although the majority showed withdrawal was a medically led task, the results showed practice variations between units, with the key tasks related to withdrawal being carried out by nurses on many occasions. Only one unit followed a guideline (adapted from the Liverpool end of life care pathway; MCPCIL, 2010). As the scoping exercise only surveyed 22 of the 36 PICUs listed on the PICANet database (Paediatric Intensive Care Audit Network, 2012; the organisation responsible for collecting PICU data in the UK) there may be units with more robust guidance, but those managers who responded (only 8) were not aware of this, if it existed.

Survey conclusions

It is acknowledged the low survey response rates mean they cannot be considered as robust forms of evidence. Yet they do provide a starting point for a broader discussion on the legal and professional context of nurses' roles in terminal care. The qualitative responses in the local survey suggested that nurses are sympathetic to carrying out withdrawal of treatment on occasion, yet in doubt about its legal status and wanted additional guidance. Meanwhile the scoping exercise confirmed withdrawal is an occasional part of nursing practice, and that the lack of guidelines is widespread. In order to clarify the current situation and shed light on the legality of the practice, legal research was undertaken. Before presenting these findings, however, it is pertinent to review the ethical position of withdrawal.

Ethical considerations for nurse withdrawers

Ethical arguments defending withdrawal of treatment command a wide spectrum of support, with few voices maintaining human life is inviolable in any circumstance (Keown, 2002). The principle that individuals are best able to determine their own interests allows patients to refuse life sustaining treatment against the advice of clinicians, provided they are mentally competent and fully aware of the consequences this decision will bring, is widely accepted. Similarly the criteria drawn up by the Royal College of Paediatrics and Child Health (2004), that withdrawal is ethically supportable where a child is brain dead (the irreversible end of all brain activity), in a persistent vegetative state, or where treatment offers no chance, serves no purpose or is unbearable given the intractable nature of an illness, are equally applicable to adults. Although something approaching consensus exists, there are nevertheless arguments suggesting there is something distinctive about the role of a nurse that prohibits her from being actively involved in the withdrawal process. One such argument suggests that the essence of nursing is about care and the preservation of life, and as such the active withdrawal of treatment by a nurse would be in opposition to this essence. At the heart of such arguments are questions of the identity and status of nursing that are hotly debated. For instance McCabe (2007) suggests that the basic values of nursing are to care for and foster life and as such they are incompatible with actions that may bring about death (although she discusses euthanasia rather than withdrawal). Others suggest nursing is a holistic approach to treatment that might embrace any activity that benefits the patient (Chiarella, 2002). Such positions are deeply entrenched and would need lengthy digressions to discuss here; certainly no nurse should feel compelled to undertake withdrawal against their beliefs, however it is suggested practitioners who consider there are benefits to the patient in having a nurse withdraw treatment should be able to

rely on the moral arguments detailed above. One example of patient benefit in allowing a nurse to withdraw is where there is a significant delay in withdrawal due to the unavailability of a senior doctor. Such delays may cause unbearable distress for the patient's family, and, by implication, the patient themselves.

The legal position

While a full discussion of the complexities of the legal position is to be found elsewhere (Birchley, 2012), the key themes may be of interest to practitioners and are reprised here. The legal position governing the withdrawal of treatment is found almost entirely in case law, that is, court judgements (Campbell et al., 2001). In case law (so called "common law") judges determine the law by using the principle of precedent, where the highest court judgment upon an issue must be followed. Even in new and complex situations, the courts try to find principles in other cases that are then applied to the circumstances of the case at hand (Forrester and Griffiths, 2010). Because there are no actual cases where a court has considered the actions of a nurse withdrawing treatment, an idea of the legal position can be gauged by looking for precedents in parallel cases where similar issues have been considered. By examining what precedents the courts have set about the withdrawal of treatment per se, and how the courts have considered the legal responsibilities of nurses, it is possible to suggest what the courts might say about nurse withdrawal. As it will transpire, the courts are very particular that it is doctors who withdraw treatment. Nurses might, however, be allowed to carry out withdrawals because the courts consider that nurses are often only instruments of doctors (see below for discussion ie. *Royal College of Nursing v Department of Health and Social Security* [1981] 1 All ER 545 hereafter: *RCN v DHSS*). This second point creates a sharp disagreement with nurses' responsibilities under their code of professional practice (NMC, 2008) and nurses contemplating withdrawing treatment should recognise they are in a potentially vulnerable position. The implications of this disagreement shall be examined later. For the time being the precedents governing, first, withdrawal of treatment, and secondly, the status of nurses, shall be discussed.

The law governing withdrawal

Significantly, case law discusses withdrawal exclusively as an activity of "doctors" (*Airedale NHS Trust v Bland* [1993] AC 789 hereafter *Bland*). This is not just an idle turn of phrase; the courts treat acts of quasi-withdrawal by members of the public in severe terms, and the legality of nurses

carrying out withdrawal of treatment rests heavily on their perceived relationship to doctors. It is useful background to consider how doctors are allowed to withdraw treatment and ask ourselves if the same reasoning can apply to nurses: Much of the fine detail can be found in *Bland*.

Anthony Bland was left in a persistent vegetative state after being asphyxiated in the Hillsborough Football Stadium disaster, and after three years his family and doctors, considering he had no hope of recovery, applied for permission from the courts to withdraw treatment – in his case nutrition and hydration - to allow him to die. In its judgment, the court determined that medical treatment could legitimately be withdrawn as it no longer served Mr Bland's best interests. As they considered tube feeding to be a medical treatment they concluded his doctors were no longer under a duty to artificially feed Mr Bland and could allow him to die.

In the Bland case, the courts sanctioned starvation as a means of ending life. The court's position becomes clearer if the underlying precedent is considered: Legal perspectives start with withdrawal being a type of killing like murder or manslaughter, and because of this a special defence is needed to prevent a person who withdraws treatment being found guilty of these offences (Herring, 2006). A well intentioned motive does not stop killing from being illegal, and arguably the 'killing' resulting from withdrawal of treatment is extremely serious because it is both caused and intended by the perpetrator, the two components of a successful murder conviction (Herring, 2006). However, when doctors withdraw treatment, the courts have reasoned it is not murder because the patient's underlying illness causes their death; withdrawal of treatment just allows nature to take its course. In legal terminology withdrawal of treatment is therefore an omission rather than a positive act and doctors do not cause the death, so the first element of murder, causation, is negated. The necessity of Mr Bland's death being an omission is why the court sanctioned the (to critics, bizarre) path of halting tube feeding to withdraw treatment (Herring 2006; Huxtable, 2007). There is a further legal pitfall which may make the withdrawer liable to a lesser charge of manslaughter; healthcare professionals are within a class of persons who (arguably) have a legal duty to act to save life; however, by allowing that it is a doctor's duty to act in the best interests of their patient, the courts can be satisfied that these best interests are served by the doctor deciding not to act (Huxtable, 2007), a position now found in section 4 (5) the Mental Capacity Act 2005 (in children the centrality of acting in their best interests is echoed in the Children Act 1989). This legal reasoning has been used to allow doctors to withdraw life sustaining treatment by other means, with withdrawal of artificial ventilation being the most common in intensive care. However, it is noteworthy that the courts talk exclusively of "doctors" when discussing these matters, rather than other health professionals.

Could nurses legally be withdrawers?

Could the legal arguments for nurse enacted withdrawal be the same as those for withdrawal enacted by doctors? For this to be the case requires acceptance that the exclusive use of the word “doctors” in the relevant case law was just shorthand for any legitimate person. To do this it must be determined who a legitimate person might be. Essentially, the answer to this seems to be somebody who is following doctors’ orders. A recent discussion by Huxtable (2007) suggests a member of the public, acting outside doctors’ orders, cannot withdraw treatment. This is starkly illustrated by the case of Abigail Watts, a 14 month old, chronically dependent on ventilation (Barsby, 1998), and already the subject of a not for resuscitation order. Abigail died following displacement of her tracheostomy tube which a jury found had been removed by Abigail’s mother. Although the court acknowledged that she was dedicated to Abigail’s care, she was convicted of manslaughter; the similarity of her actions to a withdrawing doctor was immaterial (Huxtable, 2007).

However there is a story in the nursing press of a nurse under doctors' orders escaping prosecution for actions that seem very similar to withdrawal. John Lovell was a ventilator dependent intensive care patient who repeatedly disconnected his ventilator tubing and begged his nurses to let him die (Rowe, 1994). After several days of this, his consultant instructed a nurse to turn off Mr Lovell's ventilator disconnection alarm and give him diamorphine to make him comfortable (Cassidy, 1994). Mr Lovell died soon afterwards having disconnected his ventilation tubing once more. The coroner exonerated the nurse, characterising the incident as a case of a patient exercising their choice in determining treatment.

In the search for legal precedents that might distinguish nurses from members of the public from nurses, and thus establish the legal position of nurses withdrawing treatment on PICU, the story of John Lovell gives an indication they might not be prosecuted for such actions, but does not provide the precedent sought because it was not a court case. To find precedents that establish the legal position the very few cases where judges have considered the status of nurses in the law must be examined. Although these cases do not directly discuss PICU or withdrawal of treatment, they provide precedents that suggest nurses, by following doctors’ orders, may defend their actions as treatment withdrawers in the eyes of the law. Yet the detail of the law is uncomfortably different to the expectations of the current code of professional practice (NMC, 2008), suggesting both the law and the code are in need of reform.

“...under the control of the doctor...”

The most recent case where the status of nurses is considered is *RCN v DHSS*. This concerned the legality of nurses performing termination of pregnancy¹ using the extra-amniotic method, where a catheter is inserted via the cervix into the uterus, and an abortifacient infusion is instilled causing the miscarriage of the fetus. A Department of Health and Social Security (DHSS) circular advised that nurses should be able to connect and administer the abortifacient infusion used to terminate the pregnancy, provided a doctor had decided on the treatment and inserted the catheter. The Royal College of Nursing (RCN) contended that this advice was not correct in law, as the Section 1 of the Abortion Act 1967 states:

...a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical practitioner

Doctors thus identified in law as the only professionals allowed to terminate pregnancy, the RCN argued abortifacient administration by a nurse was in contravention of the law. The courts disagreed and found in favour of the DHSS. In their ruling they suggested aspects of the Abortion Act implied that a team effort was envisaged, so its protection must extend to the team at large, not just the doctor. But this team effort was not one of equals:

“I think that the successive steps taken by a nurse in carrying out the extra-amniotic process are fully protected provided that the entirety of the treatment for the termination of the pregnancy and her participation in it is at all times under the control of the doctor even though the doctor is not present throughout the entirety of the treatment” Lord Roskill, *RCN v DHSS*, at 838.

This ‘remote controlling’ of nurses has important implications. Nurses are independent practitioners, and even if following a doctor's instructions, a nurse may still feel they are exercising considerable autonomy. Yet *RCN v DHSS* follows a legal precedent that has strong implications for nurses who withdraw treatment on doctors’ orders, by suggesting nurses' primary duties are to

¹ *RCN v DHSS* represents a rare parallel case from which we can draw conclusions about the approach of common law to nurses who, on doctors orders, perform activities that are illegal for the general public. Bearing in mind that this paper is not for a legally trained audience it is worth making it plain that the parallels in this case are the way the law treats nurses who are following doctors orders, rather than any comparison of termination of pregnancy with withdrawal of treatment.

doctors, rather than patients - an idea strongly at variance to the code of professional practice (NMC, 2008). Further detail of this precedent can be gleaned from the case *Gold v Essex County Council* [1943] 2 KB 293, a case that settled the question of whether hospitals or doctors were liable for nurses' actions. Although delivering a judgement that the hospital was vicariously liable for nurses' actions, this liability seems to flow through a doctor as both judges voiced similar opinions that, wherever the liability falls, a nurse *cannot* be negligent *when carrying out a doctor's orders*:

“If the surgeon gives a direction to the nurse and she carries it out, she is not guilty of negligence even if the direction is improper” Goddard LJ, *Gold v Essex*, at 310.

Although this precedent indicates that a nurse who withdraws treatment could be acting legally, it seems to have taken an apparently sensible principle – that healthcare is a team activity with doctors in charge - to absurd extremes, as it indicates a limitation in the duty of care owed to the patient, creating a fundamental inconsistency with nursing's code of professional practice, which declares:

“As a professional, you are personally accountable for actions and omissions in your practice and must always be able to justify your decisions.” (NMC, 2008).

The legal and professional risks for nurse withdrawers

The NMC's expectation of professional responsibility extends far beyond the legal expectation of nurses blindly obeying doctors' orders and provides scope for sharp differences of response between courts and regulators. Nurses practising treatment withdrawal need to recognise their vulnerability. A nurse defending their actions as a withdrawer may be judged according to different standards by the law and the NMC. It is quite possible that a nurses' conduct be viewed sympathetically by the courts, yet severely punished by the professional regulator depending upon their view of the public interest. Meanwhile, although it seems likely that nurses would have a legal defence for their part in withdrawing treatment, the legal landscape is not without its problems: Firstly, as has been detailed, because withdrawal is circumstantially similar to murder, case law gives doctors a defence against it. But a nurse facing the same legal challenge would find that a defence based on following doctors orders would be inadmissible, because it is no defence against

murder to claim somebody told us to do it. Even in a civil case, where a defence of vicarious liability exists, it may not withstand judicial scrutiny if the underlying principle is perceived as irrational, as recent cases have seen the courts keen to tackle apparent irrationality in medical negligence law (Brazier and Miola, 2000). Furthermore, any implication that nurses' primary duty is not to patients contradicts legislative moves to support whistle-blowing under the Public Interest Disclosure Act 1998.

Implications for practice

Nurses practising withdrawal are vulnerable. While it is unlikely that either the professional regulator or the courts would initiate action independently, in the event of a serious complaint where their practice was scrutinised, the current position is precarious. In the light of this the authors have the following recommendations:

Firstly, there is a need for guidance and legal clarity. The role of nurses as independent professionals is poorly understood by the courts. Moreover, the system of precedent in common law inclines such law to be poorly adapted to the rapidly changing circumstances of professional practice. Nursing is not unique in this respect, and nurses can learn from the experience of medicine, as judges have made use of professional guidance in the past to fill the gaps in their knowledge of practice. There is a strong case for nurses themselves to develop guidance on treatment withdrawal that better reflects current practice. Much of the law surrounding end of life care can be criticised for its irrationality (Huxtable, 2007). The controversy surrounding many of the issues at stake mean that parliament has been unwilling or unable to formulate laws that would provide a more rational framework. While the risks to professionals are minimal, they do exist, and nurses must continue to agitate for parliamentary legislation that recognises their sometimes ambiguous position in the workplace.

Secondly, should nurses be withdrawers? Nurses need to decide what they consider acceptable aspects of their practice. If being active withdrawers of treatment is incompatible with the underlying philosophy of nursing, if it asks too much of individual practitioners, then nurses must clearly vocalise this. Nurses have expressed concern both for their NMC registration and the potential for legal comeback if they have been involved in actively withdrawing treatment. Both the courts and the NMC (eg. In the controversy surrounding the case of Margaret Haywood, who was deregistered for publicising the maltreatment of patients; see: Smith, 2009) have shown questionable judgement at times when considering the actions of nurses. There are of course risks

of complaint from families or members of the public in contentious withdrawal cases. Yet the legal and professional risks for nurses engaged in withdrawing treatment from patients on medical advice and direction are minimal. Neither the courts nor the NMC have a professed desire to punish nurses engaged in legitimate activities. Achieving consensus with families about futile treatment and clear discussion and documentation of withdrawal rationale help minimise such risks as there are. The focus on individual responsibility within the NMC code of conduct ignores the team nature of much hospital work. While individual responsibility is important for patient safety, a more nuanced position on the realities of working in a subordinate position within this team is needed.

Limitations

Although the legal research was rigorous, the survey study has a large number of limitations that limit its usefulness. At 15%, the response rates to the local study were well below the 80% that is generally considered acceptable for questionnaire based research (Gerrish and Lacey, 2006). The national scoping exercise surveyed only 22 of 36 UK PICUs, of whom only 36% responded, meaning that it may not be an accurate reflection of national practice as a whole. Both questionnaires were insufficiently rigorous, and the researchers did not consult with the trust's audit department, leading to a lack of experienced input in their design. Furthermore there was no substantial piloting of the local survey and none at all of the national survey, again weakening the efficacy of any conclusions. The study must therefore be seen as a preliminary exercise, and further research will need to be performed to test the accuracy of its conclusions.

Conclusion

Despite their methodological weakness, the local and national surveys indicate nurses may be the active withdrawers of life sustaining treatment in terminal care scenarios. Qualitative responses suggested nurses need solid guidance about the scope of their practice in this area. There remains much more work to be done on this topic. Best practice needs to be elucidated and this information formed into a national guideline and debate needs to be take place to decide the acceptability of treatment withdrawal within nursing practice. Although the authors consider there is an adequate moral defence of nurses' involvement in withdrawal, their legal research suggests that, while potentially offering nurses protection, the legal principles that underlie such protection may be

inconsistent with nurses' obligations under NMC code of professional conduct. This raises the unsatisfactory prospect of a defence based upon these principles placing a nurse at risk of censure by the NMC. Such risks may be met by formulating guidelines for practice for adoption by relevant national bodies. Such guidelines could inform both the courts and the NMC of the scope of legitimate practice if such practice underwent scrutiny. It is unacceptable that nurses should run risk of censure for legitimate actions in the terminal care of patients; it is within the hands of intensive care practitioners to take steps to prevent this.

What Is Known About This Topic

Withdrawal of life saving treatment is a common modality of death in PICU.

There is no national guidance on how the process should be managed.

The needs and wishes of parents and children around the time of withdrawal of treatment are poorly documented.

The legal position of nurse withdrawers has not been investigated.

What this paper adds

There is anecdotal evidence that nurses sometimes perform the key tasks in treatment withdrawal.

The paper attempts to clarify the legal position of nurses who withdraw treatment.

National guidelines are needed to ensure consistent best practice around the UK and inform the law.

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