



WITHHOLDING OR WITHDRAWING MEDICAL TREATMENT FROM SEVERELY ILL NEONATES IN MALAYSIA: REGULATORY GAP AND UNCERTAINTY

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Abstract

There are various circumstances that require medical practitioners to decide to withhold or withdraw medical treatment from severely ill or impaired neonates. Not only is it ethically complex to make such a difficult decision, but they may also be exposed to legal liabilities. Therefore, it is crucial for medical practitioners to have access to comprehensive guidance and legal rules. Unlike jurisdictions such as the UK and the Netherlands, which have specific legislation, guidelines, and legal precedents that serve as points of reference, there is a gap in Malaysia's regulatory system, surrounded by a climate of uncertainty. Based on qualitative and doctrinal studies, this article highlights the regulatory gap as well as selected case laws in the United Kingdom that can be used to reform the existing decision-making mechanism in Malaysia to protect doctors who decide to withhold or withdraw medical treatment from critically impaired neonates. This article argues the existing national clinical guidelines, which play an important role as the sole guiding document for Malaysian medical practitioners, lack comprehensive and clear guidance. This is compounded by the lack of clarity regarding the legality of withholding or withdrawing medical treatment from severely ill neonates, as there is no specific legislation or case law regulating this area. The Child Act 2001 and the Malaysian Penal Code are the two relevant legislations that shed some light on this issue and reflect the regulatory gap between the national clinical guidelines and the legal framework. Hence, amendments to the Malaysian Penal Code and the Child Act 2001, together with improvements to the clinical practice guidelines, are needed to strengthen the regulation of withholding or withdrawing medical treatment from severely impaired neonates in Malaysia.

Key words: Withholding treatment, withdrawal of treatment, neonates, severely ill

I INTRODUCTION

Margaret Brazier stated, “*Advances in medical science, extending life at one end and bringing new hope to the childless at the other, have given rise to intricate problems of law and ethics*”.¹ The advancement in medical technology has enabled medical practitioners to use innovative medical services and equipment to save patients with relatively very poor health conditions, which may not be possible in the past. Even though it should be applauded, this advancement has also given rise to various ethical and legal dilemmas in the medical field. For instance, with current technology, the life of a neonate who is severely ill can be prolonged. However, one would ask whether medical treatment should continue to prolong the life of neonates with such health conditions or should medical practitioners withhold,² or withdraw,³ the treatment to let the neonates die naturally? This practice is also known as selective-non-treatment, as decisions to treat, withhold or withdraw medical treatment should be made selectively looking into various factors, especially the neonate’s best interest. In this situation, medical practitioners are shouldered with a heavy responsibility to make a decision that is in the best interest of the neonates and also to guide family members or relatives to decide whether the treatment should be continued, withheld or withdrawn.

One of the fundamental principles in medical law and ethics is the principle of sanctity of life. Under this principle, every life is considered sacred and it is impermissible to kill innocent person in any circumstances,⁴ which requires medical practitioners to preserve life as it is sacred. They also must respect patients’ right to life. Many scholars have also argued that medical practitioners have the moral duty to do their best to save lives. However, it has been widely debated that this principle is not absolute, especially when a treatment is futile and the burden of the treatment outweighs its benefit for the patient, such treatment can be withdrawn. There are a number of decided cases in jurisdictions such as the United Kingdom (UK) and the United States of America (USA) that are in favour of this argument.⁵ In those countries, under certain circumstances, life-sustaining treatments can be withheld or withdrawn, if it is in the best interest of the severely ill neonates.

In the UK’s landmark case, *Airdale NHS Trust v Bland*,⁶ Lord Goff emphasised that the principle of sanctity of life is not absolute and it must be subject to the right of self-determination.⁷ Hence, if a patient is an adult of a sound mind, his autonomous decision on continuation or withdrawal of medical treatment must be respected by his doctor even if his decision may cause harm to himself. However, neonates are non-autonomous agents who cannot decide for themselves. Hence, similar ethical and legal principles established in *Airdale* cannot be applied in cases involving neonates. Challenges for the medical team spurs when decision must be made on whether to continue, withhold or withdraw medical treatments from neonates whose health conditions are severely compromised. Ethical dilemma may arise in two main situations.

First, when medical treatment for a neonate is prognosed to be futile. For example, when a neonate is born without brain, also known as anencephaly, death would be inevitable

¹ Margaret Brazier, Emma Cave and Rob Heywood, *Medicine, patients and the law* (Manchester University Press, 6th ed, 2016) xvi.

² ‘Withholding medical treatment’ is not initiating medical treatment from the very beginning: Ministry of Health Malaysia, *Clinical Practice Guideline 2005: Withholding and Withdrawal of Life Support from Children* (Guideline, 2005) app 1 para 2 <<https://mpaeds.my/wp-content/uploads/2018/05/Withholding-and-Withdrawing-of-Life-Support-in-Children.pdf>> (‘CPG 2005’).

³ ‘Withdrawing medical treatment’ is when medical treatment is initiated and later withdrawn at certain point: *ibid* app 1 para 2.

⁴ Clarke S., ‘The sanctity of life as a sacred value’ (2023) 37(1) *Bioethics*, Jan; 32, 33.

⁵ *Re T (Wardship: Medical Treatment)* [1997] 1 WLR 906 (Court of Appeal); *Re B (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 927; *Re J (A Minor) (Wardship: Medical Treatment)* [1991] 1 Fam 33.

⁶ [1993] 1 All ER 821.

⁷ *Ibid* 866.

regardless of aggressive medical intervention. Hence, provision of medical treatment for anencephalic neonate is considered to be futile. The word “futile” originated from Latin, “*futilis*” which means “leaky”. This word was used in Greek mythology narrating Danaus’ daughter who drew water in a leaking bucket.⁸ Hence, futile means “fruitless”. In medical context, “futile medical treatment” refers to medical treatments that are not beneficial to the patients, and does not achieve the treatment’s objective or it merely artificially prolongs a patient’s life.⁹ Even though literally it appears to be simple in reality, making a clinical judgment on whether a particular medical treatment is beneficial or futile for a patient may be difficult. This is because of its conceptual vagueness in the first place. Futility can be divided into Physiological Futility, Quantitative Futility and Qualitative Futility. Physiological Futility sets the objective or aims of a medical treatment as a threshold to determine whether a particular medical treatment for a particular patient is beneficial or futile. Andrew McGee,¹⁰ and Shaun Pattinson,¹¹ had explained the difficulty in applying this concept. For example, McGee argues that if the purpose or aim of the treatment is to sustain life, then medical treatment to merely sustain life cannot be said to be futile, even if the patient is permanently unconscious as Anthony Bland.¹² However, the medical treatment may be qualitatively futile for such patients since the treatment results in poor outcome even though it works biologically to sustain life. This reflects the difficulty in applying the ethical principles to determine continuation, withholding or withdrawal of medical treatment.

Second, a dilemma arises when a neonate would survive with provision of medical treatment but will lead a life that falls short of standard quality of life. This calls for assessment of prognosis of quality of life of a severely ill neonate upon provision of medical treatment. For instance, a spina bifida neonate who is born with spine and muscular disorder can undergo medical treatment which will be able to prolong his or her life. However, the neonate will have ambulatory challenges, and constant medical treatment will be required. The neonate may also have to endure numerous surgeries throughout his or her life. Hence, the neonate will be dependent on other family members throughout his or her life. This means that the quality of life of the neonate when growing up may fall shorter than that of the ordinary quality of life that is normally enjoyed by other children.

This is also a very complex and ethically difficult concept as there is no specific guideline to define what amounts to good or poor prognosis of quality of life. It then depends on individual perspective of the doctors attending to the severely impaired neonates. A medico-legal lawyer who was interviewed,¹³ explained that the complexity and subjectivity of this concept can be described by using a violinist as an example. If a violinist loses his specific fingers that he needs to play violin, to him, his quality of life may appear to be poor even though to others, it will not affect their quality of life. Richard McCormick is amongst the ethicist who argues that even though he agrees with the sanctity of life principle that considers all lives sacred, he opines that medical treatment should only be provided for neonates who have potentially human relationships.¹⁴ The issue becomes more complex for neonates as neonates are yet to experience life, and clinical judgment has to be made by doctors and the medical team on the

⁸ Sophie Kasimow, ‘A New Approach to the Medical Futility: Reframing the Debate’ (2005) 14(1) *Macalester Journal of Philosophy* 112, 112–119 <<https://digitalcommons.macalester.edu/philo/vol14/iss1/10/>>.

⁹ JK Mason and GT Laurie, *Mason and McCall Smith’s Law and Medical Ethics* (Oxford University Press, 12th ed, 2023) 542.

¹⁰ Andrew McGee, ‘Defending the sanctity of life principle: A reply to John Keown’ (2011) 18(4) *Journal of Law and Medicine* 1,16. <[https://eprints.qut.edu.au/42598/1/Defending+the+Sanctity+of+Life+Principle+\(ePrints\).pdf](https://eprints.qut.edu.au/42598/1/Defending+the+Sanctity+of+Life+Principle+(ePrints).pdf)>.

¹¹ Shaun D Pattinson, *Medical Law & Ethics* (Sweet & Maxwell, 2009) 560.

¹² McGee (n 10).

¹³ Interview with a medico-legal lawyer (Sivameenambigai a/p Veeriah, Kuala Lumpur, 25.10.2009)..

¹⁴ RA McCormick, ‘The Quality of Life, The Sanctity of Life’ (1978) 8(1) *Hastings Center Report* 30, 30–6 <<https://pubmed.ncbi.nlm.nih.gov/624620/>>.

neonates' prognosis of quality of life. As quality of life is a subjective matter, neonates with similar health conditions may be subject to different decisions if placed under different doctors.

The complexity is worsened by the fact that medical practitioners owe an ethical obligation to save their patients' life. All medical practitioners are under the Hippocratic Oath which binds them not to cause "harm" to their patients. "Causing harm to patients" may also extend to prolonging a medical treatment that burdens the patient outweighing the benefits of the medical treatment. To address such difficult ethical dilemma, this article argues that it is vital to have clear regulatory framework and policy to provide clarity to the medical practitioners in relation to withholding or withdrawing medical treatment from severely ill neonates and their legal position when they make such clinical decisions.

In Malaysia, there is no specific legislation regulating continuation, withholding or withdrawal of medical treatment for both adults and neonates in the country, as highlighted by Puteri Nemie Jahn Kassim *et.al* and Dr Mohammad Firdaus *et.al*.¹⁵ Nevertheless, the Ministry of Health, Malaysia has produced *Clinical Practice Guideline 2005: Withholding and Withdrawal of Life Support from Children (CPG 2005)* which provide ethical grounds for its permissibility and prescribes circumstances when life support may be withdrawn from children including neonates. Notwithstanding, based on findings obtained from both doctrinal and qualitative studies conducted between 2008 and 2021 with relevant stakeholders in Malaysia, this article argues that the guidelines are not comprehensive in providing reference for standard of care required of medical practitioners in deciding to withhold or withdraw medical treatments. In addition, this article also argues that withholding or withdrawing medical treatment from severely ill neonates may still render the doctors liable under the Penal Code and/or the Child Act 2001 (the CA 2001) in certain circumstances despite adhering to the guiding rules provided by the guidelines and consent given by parents or guardians. This shows that there is a gap between the guidelines and the relevant legal framework and this can lead to a climate of uncertainty among medical practitioners in Malaysia. They will be facing a heavy moral and legal burden if they find themselves in such situations described above. This raises serious concerns about the legal status of withholding or withdrawal of treatment from severely ill neonates in Malaysia which requires attention.

II METHODOLOGY

This study adopts a mixed method; the primary data were gathered via qualitative methodology, and secondary data were acquired through doctrinal method.¹⁶ Qualitative methodology was adopted to understand the reality within the hospital settings. This is vital to analyze various legal and ethical dilemmas surrounding withholding or withdrawal of medical treatment in the Neonatal Intensive Care Units (NICU). The primary data of this study was acquired through an empirical study involving semi-structured interviews with eight neonatologists in Klang Valley, Perak and Negeri Sembilan. A medico-legal lawyer in Kuala Lumpur was also interviewed to acquire the perspective of a lawyer. Ethical approval of the hospitals' Research Departments or Ethical Committees was applied for and obtained to interview the relevant respondents. Purposive sampling method was used to select the interviewees based on their knowledge and

¹⁵ Puteri Nemie Jahn Kassim and Fadhilina Alias, 'End-of -life decisions in Malaysia: Adequacies of ethical codes and developing legal standards' (2015) 22(4) *Journal of Law and Medicine* 934, 935 <[https://www.researchgate.net/publication/280562104_End-of life_decisions_in_Malaysia_Adequacies_of_Ethical_Codes_and_Developing_Legal_Standards](https://www.researchgate.net/publication/280562104_End-of_life_decisions_in_Malaysia_Adequacies_of_Ethical_Codes_and_Developing_Legal_Standards)>; Loh Kah Hey and Mohammad Firdaus Abdul Aziz, 'The Withdrawal or Withholding of Life-Sustaining Treatment: The Future in Malaysia' [2021] 1 *LNS(A)* v.

¹⁶ The empirical data provided in this writing was gathered during the author's doctoral study: Sivameenambigai a/p Veeriah, "THE PRACTICE AND LEGAL PERSPECTIVE OF WITHHOLDING OR WITHDRAWING MEDICAL TREATMENT FROM SEVERELY IMPAIRED NEONATES IN MALAYSIA"(PhD Thesis, Universiti Malaya, 2024).

expertise. As for the secondary data, reference was made to literature, clinical guidelines, statutes, books, journals and court decisions to gather relevant information. The main statutes referred to are the Child Act 2001 and the Malaysian Penal Code. Even though there are various Code of Medical or Professional Ethics in Malaysia, the *Clinical Practice Guideline 2005: Withholding and Withdrawing of Life Support in Children* issued by Ministry of Health, Malaysia, is the most significant source of analysis for this study as it highlights the regulatory gap when measured with the existing legal framework. Explanatory Sequential Design was used to combine both methods;¹⁷ the relevant clinical guidelines and legal framework were identified first to determine existence of its gaps using doctrinal research. Thereafter, qualitative interviews were conducted to understand how legal practitioners practice withholding or withdrawing medical treatment from severely ill neonates despite the existence of the said gap. This will then establish firstly, whether reformation is necessary and second, what are the reformations that need to be executed to fill the gap.

III GLOBAL CONTEXT

In general, every human person has the right to life as accorded by the International Human Rights Law (IHRL),¹⁸ and the *Universal Declaration of Human Rights* (UDHR) is one of the core documents that forms foundation for International Human Rights Law. Article 3 of the UDHR states “everyone has the right to life, liberty and security of a person”. Article 2 further asserts that everyone is entitled to this right regardless of any kind such as race and birth. In the UK, article 2 of its Human Rights Act 1998 (HRA 1998) provides that “right to life means nobody, including Government, can try to end your life”. In fact, Article 2 of the HRA emphasises that the Government has a duty to protect everyone in general and individuals whose lives are at risk. In Article VI (1) of the *United Nation Convention on the Rights of the Child*,¹⁹ it provides that every child has the right to inherent right to life and states are given the responsibility to ensure the survival and healthy development of the child without any discriminations based on amongst others, race, colour, religion and gender.²⁰ Nonetheless, the right to life can be said as not absolute, depending on the circumstances, particularly in medical context involving ill neonates.

Hence, across the globe, there are countries that have legalised euthanasia and/or withdrawal of medical treatment from both adult and children under stringent protocols such as Belgium and the Netherlands.²¹ Netherlands created a milestone by passing its *Groningen Protocol (GP)*,²² legalising euthanasia and withholding or withdrawing of medical treatment

¹⁷ Mohammad Abu Sayed Toyon. ‘Explanatory sequential design of mixed methods research: Phases and challenges’ (2011) 10(5) *International Journal of Research in Business and Social Science* 253, 253–260. In the context of this study, the doctrinal study is done first to understand the policies and legal framework to identify the gap and thereafter, qualitative interviews are carried out to see how the stakeholders practice in reality despite the gap.

¹⁸ International Human Rights Law accords universal legal protection to individual’s various fundamental rights such as right to life, freedom, right to basic necessities and right to be protected from abuse or torture regardless of status or gender. It is developed through various United Nations treaties and customary laws imposing obligation upon states to implement the said rights via their legislations. For example, the United Kingdom is a country that has ratified international human rights treaties and it implements the protections for human rights via its *Human Rights Act 1998* (UK).

¹⁹ The *Convention on the Rights of the Child* defines a child to refer to all human beings below the age of 18 unless the law of a country states otherwise: *United Nations Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 1 <<https://www.unicef.org/child-rights-convention/convention-text#>>.

²⁰ Ibid art 2 <<https://www.unicef.org/child-rights-convention/convention-text#>>.

²¹ See *Groningen Protocol for Netherlands* and *Euthanasia Act 2002* for Belgium.

²² The *Groningen Protocol* was drafted by a team that included Eduard Verhagen to encourage discussion with proper transparency among the public regarding the euthanasia of newborns. See Eduard Verhagen and

under stringent circumstances which may set a good threshold model for a country like Malaysia in the context of withholding or withdrawing medical treatment from severely ill neonates.

The *Groningen Protocol* permits termination of life of a patient be it actively or passively under stringent conditions as follows:

- i. Only neonates who fall under either one of the three categories listed can be considered for life termination or selective-non-treatment under this Protocol. This includes neonates born with no chance for survival, neonates who are born with severe impairment and are dependent on intensive care such as ventilator or who will be subject to unbearable suffering.
- ii. The termination of life under *GP* must comply with the following procedures:
 - a. the diagnosis and prognosis must be certain.
 - b. the element of hopeless and unbearable suffering must be present.
 - c. the diagnosis, prognosis and unbearable suffering must be confirmed by at least one independent doctor.
 - d. both parents must have given informed consent and the procedure must be performed in accordance with the accepted medical standard.
- iii. the *GP* stipulates transparency by requiring the medical team to mandatorily furnish material information about the euthanasia including diagnosis, prognosis, how the decision for euthanizing was made, details of consultation with the medical team including securing second opinion and recommendations made by the consultation team, the detail regarding implementation of the procedure and steps taken after death.

At this point, it is important to notice that an important step to be taken is reporting the euthanasia to the prosecuting authority with all the documentations to support the decision. The Attorney General office will have the power to evaluate each decision to determine if the life termination was ethically justified and complied with the *GP*'s mandatory requirements. The Attorney's office is given power to prosecute any suspicious life-termination cases within hospital settings. This promotes transparency and provides clarity in legal position of doctors who decide to withhold or withdraw medical treatments in Netherlands, and their decisions are subject to review by the Attorney General's office.

As for the United Kingdom (UK), it faces similar scenario as in Malaysia. There is no specific legislation that permits withholding or withdrawing medical treatments from severely ill neonates in the UK and euthanasia is unlawful. The Children Act 1989 of UK imposes parental responsibility on parents and legal guardians to provide the necessities for children under their care, which includes medical treatments. Hence, failure to provide it would render parents liable under the said Act. However, it is notable that in UK, doctors are in a safer legal position since in the event of disputes between parents and doctors reaching consensus regarding medical treatment for the severely ill neonates, they often invoke the courts' *parens patriae* jurisdiction. There are various cases demonstrating circumstances in which courts have sanctioned withholding or withdrawal of medical treatment from severely ill neonates which are set as legal guidance for the medical practitioners and parents. The cases mentioned below are merely samples of cases in UK to show such invocation. Even though the court decisions have developed various principles such as best interest of the child, substituted judgement and poor

Pieter JJ Sauer, 'The Groningen Protocol-Euthanasia in Severely Ill Newborns' (2005) 352(10) *New England Journal of Medicine* 959.

quality of life assessments weighing the benefits of the treatment against the burden of the treatment, the purpose of discussing some of the UK cases in this section is merely to show how parents and doctors invoke the courts' *parens patriae* jurisdiction to obtain sanction from the court during disputes between the parties.

Cases in the UK such as *Great Ormond Street Hospital v Yates and Gard*,²³ *Alder Hay Children's NHS Foundation Trust Hospital v Evans and Ors*,²⁴ *Re T (A Minor) (Wardship: Medical Treatment)*,²⁵ *Re C (a minor) (wardship: medical treatment)*,²⁶ *Re B (A Minor) (Wardship: Medical Treatment): CA 1981*,²⁷ and *Re J (a minor) (wardship: medical treatment)*,²⁸ show how the parents or doctors take the matter at hand to the court's attention in the event of disputes between parents and doctors. Hence, when doctors decide to withhold or withdraw medical treatment from such neonates, they are safe under UK's legal framework when they obtain court's sanction for the final decision. With that, the doctors or parents who decide to withhold or withdraw medical treatments from severely ill neonates will not be liable under UK's existing legal framework.

Besides invoking courts' *parens patriae jurisdiction*, clinical guidelines have also been developed by the relevant medical bodies such as the Royal College of Paediatrics and Child Health (RCPCH). The guideline is titled "*Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*" which was published in 2014 superseding the old version published in 2004. The clinical guideline by RCPCH is constantly reviewed and updated according to the latest medicinal and technology developments by the Ethics and Law Advisory Committee together with RCPCH. For example, the clinical guideline by RCPCH in this matter was first issued in 1997 titled "*Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice*". This guideline was then revised in 2004, and the second edition of the guideline was published. It is expected that the newly updated version will be published in 2026.²⁹ Even though the ethical principles of medical futility and quality of life can be complex, this clinical guideline provides more detailed and elaborate guidance to the medical practitioners to make decisions regarding continuation, withholding or withdrawing medical treatments from children. The terms used are also updated according to the latest medical developments. For instance, the revised second edition of the guideline replace the phrase "life-saving treatment" to "life-sustaining treatment", and the latest guideline replaced the phrase "medical futility" to "limited quantity of life".³⁰ This element is also vital to ensure effective regulation by clinical guidelines for withholding or withdrawing medical treatments from severely ill neonates so that doctors are confident to rely on the said guidelines when making decisions and the guideline will be given importance to set the standard of care required of the doctors in practicing withholding or withdrawing medical treatment from severely ill neonates.

On the contrary, this study establishes that Malaysia's regulatory gap in relation to withholding or withdrawal of medical treatment from severely ill neonates exists between the practice, clinical guidelines, and the relevant Malaysian legal framework, which renders the doctors' liability to remain ambiguous when they decide to practice selective-non-treatment. In

²³ [2017] EWHC 1909 (Fam).

²⁴ [2018] EWHC 308 (Fam).

²⁵ [1997] 1 WLR 242.

²⁶ [1989] 2 All ER 782.

²⁷ [1990] 3 All ER 927.

²⁸ [1990] 3 All ER 930.

²⁹ 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (DfLT)', *Royal College of Paediatrics and Child Health* (Web Page, 2026) <<https://www.rcpch.ac.uk/resources/making-decisions-limit-treatment-life-limiting-life-threatening-conditions-children>>.

³⁰ Vic Larcher et al, *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice* (Guideline, 23 March 2015) <https://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html>.

addition, invocation of courts' *parens patriae* jurisdiction in the event of conflicts between parents and doctors is rare and Malaysian courts are yet to encounter such conflict in this context.

In the next section, this article reports the findings obtained from the empirical study that show selective-non-treatment of severely ill neonates is currently being practiced within the Malaysian hospital settings and yet, it is not regulated efficiently to protect the doctors from attracting liability and the best interest of the severely ill neonates.

A The current practice of withdrawing treatment from severely ill neonates in Malaysia

The findings of this empirical study reveal that all the paediatricians interviewed practice withdrawal of medical treatment within their Neonatal Intensive Care Units (NICU) under certain circumstances.³¹ The empirical findings reveal complexity in real practice. The practice amongst the hospitals is not uniform in various aspects. For example, only P2, P3 and P8 took a similar stand that they prefer to withdraw instead of withholding medical treatment.³² This is because, the diagnosis and prognosis made for neonates are made at the beginning stage of their lives (upon birth in most cases), which may turn out to be inaccurate as time passes by. Hence, there is a *slippery slope* at this point which renders them preferring to initiate the medical treatments and observe the neonate's responses to the said treatments before deciding to withdraw the treatments instead of withholding treatments from the very beginning.³³ P3 explained that he would try to treat the neonate first and monitor the neonate's health progress. According to him, clinical judgment must be reviewed frequently to raise the quality of survival and if the neonate's health condition is irreversible, then withdrawing the medical treatments will be in the best interest of the neonate. However, in some cases where death is obviously imminently inevitable and the treatment would be futile, some doctors would prefer to withhold the treatment.³⁴ For example, anencephalic neonates who are born with very poor chances of survival and whose death is inevitable despite provision of medical treatments. This is because parents may be emotionally affected when treatments are withdrawn upon initiating it. Hence, a neonate with similar conditions may face different decisions when placed under different neonatologists.

Another variation can be seen in recording the details of discussion and decisions when deciding to withhold or withdraw medical treatment. While the participating hospitals under the Malaysian Neonatal Registry register data of newborns and decisions made in relation to their medical treatments, the empirical finding of this study shows that, in practice, there is no mandatory requirement to record all the details for the hospitals in general. Some hospitals record the details of discussions and decisions made regarding withholding or withdrawing medical treatment, while some doctors do not maintain a detailed record despite deciding whether to withhold or withdraw the treatment. P8 shared that she records the details of discussions, decisions and the details of parties involved in the discussions to withhold or withdraw medical treatments from severely ill neonates while the rest of the neonatologist respondents stated that discussions made with their departmental colleagues are not documented. P4, for instance said:

"...we discuss with colleagues via informal discussion. It is not a formal documented discussion".

³¹ The empirical data in this study was gathered between 2009 to 2021 for doctorate studies.

³² Withholding medical treatment is not initiating medical treatment from the very beginning while withdrawal of medical treatment is when medical treatment is initiated and later withdrawn at certain point: *CPG 2005* (n 2) app 1 para 2.

³³ P2, a paediatrician from a government hospital in Kuala Lumpur.

³⁴ 'Some doctors' is in reference to P1, P4, P5, P6 and P7.

Variations in practice above show the necessity to regulate the practice of withholding or withdrawing medical treatment from severely ill neonates in Malaysia.

Nevertheless, responses by the paediatricians in relation to the main grounds, amongst others, for withdrawing medical treatments from severely ill neonates are common and can be summarised as follows:

- i. neonates who would lead a very poor quality of life.
- ii. neonates born within 26 weeks gestation,³⁵ with multiple complications that render the chances of survival of the neonates very low or even if they survive, they may suffer impairment which would affect their quality of life.
- iii. extreme premature neonates weighing 400 or 500 grams or lesser since death may be inevitable despite provision of medical treatments.

Other categories of neonates with irreversible anomalies such as syndromic neonates,³⁶ spina bifida,³⁷ severe asphyxia,³⁸ and neonates with lethal congenital anomalies who will die shortly after birth or have a short life span.

In addition, P4 explained that at times concerns arise when resources such as ventilation machines are limited. In such situations, there will be concerns on whether a ventilator for fatal neonates such as anencephalic neonates should be withdrawn to give way to neonates with better opportunities.

All the respondents admitted that in most cases parents will agree with doctors' advice, in some circumstances, conflict between parental consent and doctors' advice may arise especially if the neonate is a "golden child", which means, the neonate is their first child after a long wait, and parents are in the denial state of accepting their neonates' actual health condition. P4 explained that he will wait and convince the parents by having regular meetings with them. P8 explained that she encounters such conflicts with foreign parents who are immigrants in Malaysia. This is because they will have to bear the costs of treatment even in public hospitals and they sometimes refuse to continue medical treatment that would be costly to them despite her advice to continue the treatment. However, P8 explained that she will not withdraw the treatment and continue to convince them. P4 has also experienced a situation where he advised continuing the medical treatment for the neonate in the neonate's best interest, but the parents refused and discharged the neonate. He invoked the provisions in the Child Act 2001 that permits removal of parental custody of the neonate and went to the parents' house with Welfare Department officers to take the neonate under the Protector's custody. Hence, this shows that sometimes, doctors may have conflicts with parents to continue, withhold or withdraw medical treatments from severely ill neonates and hence, doctors' legal position must be clear when they act in the best interest of the neonates.

The above findings show that "medical futility",³⁹ and poor prognosis of "quality of life",⁴⁰ are the two main grounds to determine the best interests of severely ill neonates before

³⁵ Gestation refers to the period of baby developing inside a womb between conception and birth. Gestational age refers to how long the pregnancy is and a normal gestational period ranges from 38 to 42 weeks. Babies born below 38 weeks are considered as premature: 'Gestational age', *MedlinePlus* (Web Page, 10 January 2025) <<https://medlineplus.gov/ency/article/002367.htm>>. P8 explained that gestational period enabling successful treatment may vary with medical and technology development. For example, a neonate with lower gestational period may be able to be saved with the latest medical technology of medicinal development.

³⁶ For instance, Patau Syndrome, Down's Syndrome and Edward Syndrome.

³⁷ 'Spina bifida' is when the newborn baby has part of the spinal cord and its coverings exposed through a gap in the backbone: *Oxford Concise Medical Dictionary* (8th ed, 2009) 'spina bifida'.

³⁸ 'Asphyxia' is suffocation which is a life-threatening condition: *Oxford A Dictionary of Nursing* (5th ed, 2008) 'asphyxia'.

deciding to withdraw medical treatment in Malaysia. This article acknowledges that the current practice falls within the permissible categories, as provided in the national guidelines, which is discussed later in this paper. However, the discussion below will shed further light on complexities involved in deciding withholding or withdrawing medical treatment that further justifies the necessity for efficient regulation of the practice. This involves ethical principles that form the grounds for the decisions to withhold or withdraw the treatments from severely ill neonates that are discussed hereafter.

B Ethical concerns over the ethical grounds of medical futility and current prognosis of 'quality of life'

The two main grounds underlying the basis for withholding or withdrawal of medical treatments from severely ill neonates are poor prognosis of quality of life and futile medical treatments. Hence Besides the variations in practice, the challenges in applying the said grounds in real will also justify further the necessity of having an efficient regulatory framework governing withholding or withdrawing medical treatment from severely ill neonates.

Even though all lives are considered sacred under the doctrine of absolute sanctity of life and all non-dying neonates should be treated regardless of the outcome of the treatment,⁴¹ under the doctrine of qualified sanctity of life, medical treatment can be terminated if it is considered to be futile. The word futile originated from Latin word, "*futillis*" which means "leaky". It was used in Greek myth narrating Danaus' daughter who drew water in a leaking bucket, which was fruitless.⁴² An example of medical treatment proven to be futile is for neonates born with anencephaly condition. It is a condition affecting brain development of a neonate. The brain skull and bone are not developed around the brain that even aggressive medical treatment provision will not be beneficial as death is inevitable for such neonates by hours or days.⁴³ It is a fatal health condition. Hence, medical treatment for such neonates is said to be futile, which means fruitless or non-beneficial as the neonates' death would be inevitable, still.

However, the concept of medical futility is also not as simple as it appears above in reality. Medical futility can be divided into three categories; first, Physiological futility, in which the fruitfulness of a medical treatment is measured in accordance with the goal or objective of the treatment. If the purpose of a treatment is to sustain life, then as stated by McGee, life-sustaining treatment cannot be said to be futile for a patient who is in a Permanent Vegetative State or unconscious.⁴⁴ On the other hand, should the objective of the treatment is to reverse the health condition of a patient, the life-sustaining treatment can be said to be futile if it will only artificially prolong the life of a patient who is in Permanent Vegetative State (PVS). This application becomes more complicated if the concept is applied to patients with kidney failure who survive on dialysis weekly. If the purpose of the dialysis is to reverse the health condition of the patient, then, the dialysis treatment is futile since it will only help the patient to survive but it

³⁹ 'Medical futility' refers to redundant medical treatments since the patient's death is inevitable or it is impossible to restore the patient's health condition despite provision of aggressive medical treatment.

⁴⁰ 'Quality of life' refers to a lower standard of life in the medical context; for instance, the patient's ambulatory might be very poor, their life might be absolutely dependent on machines or other people, the patient will have to suffer the burden of going through numerous surgeries in his life in order to stay alive.

⁴¹ Paul Ramsey and Hegal Kuhse are amongst the two ethicists who are in favor of doctrine of absolute sanctity of life. This doctrine is based on theological belief that only the Creator has the right to take away the life of His creation. On secular basis, as highlighted by Lord Hoffman in the case of *Airdale NHS Trust v Bland* [1993] AC 789, human life has intrinsic value regardless of whether it is valuable to the person concerned or anyone else. Hence, it is wrong to deliberately to cause the death of another human being, even if the person is terminally ill or so disabled.

⁴² Kasimow (n 8) 113.

⁴³ Explained by P1, P2 and P4.

⁴⁴ McGee (n 10) 16.

will not enable the kidneys to function normally on their own. However, if the purpose of the dialysis is to sustain the patient's life, the dialysis treatment is not futile as the patient will be able to live a normal life provided dialysis is done. This shows the complexity of the concept. The other concepts of futility are Qualitative Futility and Quantitative Futility. Quantitative Futility defines a situation where it is clinically proven through research studies that the treatment would be beneficial to the patient while Qualitative Futility refers to treatments that will result in a poor outcome that life is not worth living and the burden of the treatment outweighs the benefit of the treatment.⁴⁵ When a decision is made that the outcome of the treatment will result in life not worth living, it is then qualitatively futile. This definition of futility is also not free from difficulties; who will decide whether it is a quality life or not? A similar difficulty is also encountered in interpreting the doctrine of prognosis of quality of life discussed below.

Prognosis of quality of life refers to the estimation of a neonate's life standard should the neonate survive with the provision of medical treatment. Will the neonate be able to live independently and meet the standard of life that is enjoyed by other normal children of his or her age? For instance, a neonate with spina bifida may be able to survive with provision of medical treatment but with very poor ambulatory ability due to his or her poor spine condition and muscle conditions. Hence, this threshold is also a ground for withdrawing medical treatments. However, in reality, the application of this threshold is not as simple as it appears to be. Determining whether the quality of life is poor or good is a very subjective matter, especially for neonates who have not experienced life yet.

The difficulty in deciding on this ground is explained by one of the Respondents who is a senior medico-legal lawyer in the country. According to the Respondent, whether the standard of a life is of good or poor quality is a subjective assessment.⁴⁶ According to him, a life that is seen to be of poor quality to one person may not be viewed so by another person and a life that is considered as of good quality may not be so to another person. For instance, to a violinist, his certain fingers are important and even if one of those fingers is affected, to him his life would be of poor quality even though others may consider his life to be of good quality based on other existing factors in his life. Hence, when deciding the quality of life of a neonate born with impairments, in reality, the decisions made by the doctors or judges (if the matter is brought to courts) may not reflect the accurate view of a neonate who has not experienced his or her life yet. Arguably, for a neonate, when he or she grows, even if he or she has severe ambulatory challenges or health conditions but his or her other good conditions in life may make him or her to view that life is worth living and is of good quality. Hence, the decisions made in hospital settings based on this ground will be tainted with medical experts' opinions and if the decision is made in a courtroom, the threshold will reflect the view of a judge who puts himself analogically in the position of the neonate (substitution judgment). Therefore, it would be difficult to justify the legality of withholding or withdrawal of medical treatment from severely ill neonates based on poor prognosis of quality of life, taking into account that neonates are non-autonomous agents who cannot provide valid consent and their life depends on the decisions made by their proxies.

This leads to a second concern; neonates with similar health conditions may be subject to different decisions since the assessment of quality of life is very subjective depending on threshold set in the mind of the doctors treating the babies. For example, P2 explained that a good quality of life outcome does not mean the neonate must be able to grow perfectly in health and be able to attend school, while another paediatrician, P3, explained that good quality of life means the neonate will not be handicapped in the next six months. This shows that in reality, severely impaired neonates' fate would depend on the interpretation of the medical team on

⁴⁵ Ryan Pferdehirt and Marissa Hernandez, 'Three Definitions of Medical Futility and How to Balance Them', *Center for Practical Bioethics* (Web Page, 2021) <<https://www.practicalbioethics.org/whats-new/three-definitions-of-medical-futility-and-how-to-balance-them/>>.

⁴⁶ The Respondent is a senior medico-legal lawyer of a legal firm in Kuala Lumpur.

what amounts to good or poor quality of life, and this may differ from one paediatrician to another. Hence, determining the legality of withholding or withdrawing medical treatment on this ground may pose some challenges bearing in mind the clinical guidelines that permit this ground for selective non-treatment.

This is worsened by the fact that there is a possibility that the doctor's prognosis of quality of life made at a very early stage of a neonate's life may be erroneous and it involves neonates who could have survived, if the treatments were continued. Hence, this would affect their right to life and is not in accordance with the "traditional and modern ethics which upholds the concept that life is sacrosanct and must be treated with utmost respect and dignity",⁴⁷ regardless of its quality of life. Keown argues "*all lives as intrinsically valuable and hence it is always* (emphasis added) *wrong to kill an innocent human being*".⁴⁸ Based on this premise, the legality of withdrawal of medical treatment based on the prognosis of poor quality of life has to be tackled with utmost caution to ensure its ethico-legal validity and at the same time, there should be no regulatory gap in order to ensure the doctors who have decided in good faith in the best interest of the neonates are protected under the law.

The discussion above highlights the complexity in doctrines and ethical principles surrounding withholding or withdrawing medical treatment from severely ill neonates. This also reflects the importance of having efficient regulatory mechanism to govern withholding and withdrawing medical treatment from severely ill neonates while also protecting the doctors who make the decisions in the said matters. The discussions below explore into the clinical guidelines and relevant legal framework, namely, the Child Act 2001 and Penal Code to determine if the practice is regulated adequately in Malaysia.

IV MALAYSIAN CLINICAL PRACTICE GUIDELINES 2005: WITHHOLDING AND WITHDRAWING OF LIFE SUPPORT IN CHILDREN (CPG 2005)

The Code of Medical Ethics (CME) and *Code of Professional Conduct* issued by the Malaysian Medical Council emphasise on the duty of medical practitioners in maintaining the utmost respect for human lives.⁴⁹ Furthermore, the *CME* asserts that a medical practitioner is obliged to ensure dignified and comfortable death for patients whose deaths are prognosed to be imminent or when life-prolonging treatment would be futile.⁵⁰ The *Code of Professional Conduct* regulates the standard required of doctors in practicing medicine and provides for disciplinary proceedings against doctors who fail to comply with such Code. It is notable that section 29 of the *Medical Act 1971* provides for disciplinary actions to be taken against doctors for, among others, professional misconduct and for disregarding their professional duties. Hence, if a doctor fails to comply with the standard required under the *Code of Professional Conduct* or duties imposed by the Code or directives issued by the Malaysian Medical Council (MMC),⁵¹ the doctor can be subject to disciplinary proceedings under the Disciplinary Board of MMC. Hence, the directives issued by the Malaysian Medical Council have significant force for compliance since non-compliance with the said directives may result the doctors in serious legal and ethical consequences.

⁴⁷ Kassim (n 15) 935.

⁴⁸ John Keown, 'Courting Euthanasia? Tony Bland and the Law Lords' (1993) 9(3) *Ethics Med* 34 <<https://pubmed.ncbi.nlm.nih.gov/11652743/>>.

⁴⁹ *Code of Medical Ethics* (Malaysia) s 1; *Code of Professional Conduct* (Malaysia) s 3.1.

⁵⁰ *Code of Medical Ethics* on 'The Dying Patient': at s 11(5).

⁵¹ Example of directives issued by the Malaysian Medical Council are *Good Medical Practice 2019*, *Dissemination of Information by Medical Practitioners*, *Consent for Treatment of Patients by Registered Medical Practitioners* and *Medical Records and Medical Reports*. Non-compliance guidelines issued by the Malaysian Medical Council may subject the medical practitioners to disciplinary action sanctioned by the *Medical Act 1971* s 29.

The Malaysian Ministry of Health issued the *Clinical Practice Guidelines 2005: Withdrawal of Life Support in Children* (hereinafter referred to as the *CPG 2005*) to provide guidance in determining continuation, withholding or withdrawing life-support in children including neonates. This guideline has no legally binding force as it is merely a guideline, and it is also not a directive under the Malaysian Medical Council that would entitle it enforced to the extent which subjects doctors to disciplinary proceedings under section 29 of the *Medical Act 1971*.

Paragraph 3.1.2 of *CPG 2005* contains provisions stipulating the grounds for withholding or withdrawal of life support specifically in neonates. The provisions explicitly highlight two main categories of ethical grounds that must be considered in determining the best interest of the affected neonates, which can be ethically justified for withholding and withdrawal of life support in neonates. The said grounds are “no chance for survival” and “quality of life issues”. “No chance of survival” refers to futile medical treatments while “quality of life issues” refers to the prognosis made based on the standard of living a neonate would endure upon or while being treated.

Para 3.1.2 a. of the *CPG 2005* provides that “no chance for survival” ground includes situations when death is imminent despite continued treatment, limited life expectancy, inevitable dependency on life-sustaining treatment, and impossibility that the neonate would ever go home.⁵² This provision is clear that when death is imminent and/or medical treatment is deemed to be not fruitful or the neonate’s health condition is irreversible, withholding or withdrawal of medical treatment is medically justified.

However, non-clarity arises in Para 3.1.2 b. of *CPG 2005* which lists conditions that may be observed to form reasons for poor prognosis of quality of life of severely ill neonates. The conditions are “*expected poor quality of life or suffering severe disabilities, severely deforming and incapacitating condition with little or no hope of achieving meaningful “humanhood”, or severe brain damage, no prospects for improvement, a high degree of suffering or unnecessary suffering, neonate’s burden of pain and suffering with treatment does not outweigh the benefits of life even if the infant is not in a terminal state, an unexpected poor developmental outcome, poor social support for disabled or a very high burden of treatment*”. The paragraph further enumerates causes that may fall under this category, such as extreme low birth weight infants and prematurity with severe complications.

Inadequacy of the *CPG 2005* in regulating selective-non-treatment of severely ill neonates can be observed via few serious concerns at this point. The conditions above are listed without having any detailed explanation as to how medical practitioners should carefully assess the conditions. Without having a proper explanation, the *CPG 2005* would not be able to effectively facilitate appropriate ethical decision-making that is in line with the standard practice in other experienced jurisdictions. For instance, one of the conditions is ‘poor social support’. If a neonate is disabled and is subject to poor social support, surely this alone does not morally justify withdrawal of life support in neonates. Another qualifying condition is ‘suffering serious disabilities’. The *CPG 2005* is also silent on the details of degree of disabilities that is recognized to be “serious” that justifies withdrawal of life-sustaining treatment. In addition, the phrase, “severely deforming and incapacitating condition with little or no hope of achieving meaningful humanhood” may give rise to various debatable thresholds to decide on whether the neonate has hope of achieving meaningful “humanhood” as the guideline does not elaborate on these criteria. Hence, the lack of elaboration explaining or providing guidance on the threshold meant in the guideline leaves the guideline in grey.

The second ambiguity in *CPG 2005* revolves around para 3.1.2 a, which provides that medical treatment is futile when “lesion will not allow meaningful survival or poor prognosis for later life”. *CPG 2005* does not explain how the poor prognosis of later life under medical futility differs from poor prognosis for quality of life. What health conditions may be considered as

⁵² *CPG 2005* (n 2) para 3.1.2 a.

poor prognosis for later life to the extent that medical treatment is considered futile?⁵³ Lack of elaboration in the *CPG 2005* to guide medical practitioners in precision gives rise to a serious regulatory gap. This is because, as highlighted by a senior medico-legal lawyer interviewed for this study, the assessment of quality of life is a subjective assessment which may differ according to each individual's background and perspective. This means a neonate with similar health conditions may be subjected to different medical treatments depending on the subjective assessment of the attending doctors and this situation may result in inequality for the severely ill neonates.

As explained earlier, ethical principles such as “medical futility” and “quality of life” are complex when indulged in depth,⁵³ and it is hereby acknowledged that it may not be possible to draft a guideline with absolute clarity in relation to ethical principles. Nevertheless, as the guideline provided by the *RCPCH* in the UK, the *CPG 2005* must at least provide details that may be of guidance to the medical practitioners and enable the courts to use the *CPG 2005* to determine the standard of care required from the doctors in the event of disputes in the courts. Lack of periodical review and updating leaves the *CPG 2005* outdated and unable to be used as a reference document to set the standard required of the doctors in deciding withholding or withdrawing life-support from children. This is evident when P8 highlighted that she does not refer to *CPG 2005* as it is outdated and not periodically reviewed while another respondent, P4, highlighted that he prefers to refer to the *RCPCH guideline* as it is updated. This shows the necessity to take the first important step in reforming the existing regulatory mechanism in Malaysia in relation to withholding or withdrawing medical treatment from severely ill neonates.

In order to have a clear and effective regulatory framework, it is also vital that the clinical guidelines and the relevant legal framework must align. This means that when the clinical guideline permits an act or omission, the doctors who decide must be free from liabilities under the law while the neonates' best interest are also protected. Otherwise, there will be inadequacy in regulating the issue at hand. Having investigated the grounds for withholding or withdrawing medical treatments from severely ill neonates provided in the *CPG 2005*, the following discussion analyses the legal position in Malaysia when doctors decide to withhold or withdraw medical treatments from severely ill neonates as sanctioned by the *CPG 2005*.

A The Child Act 2001 (Act 611) (Malaysia)

There is no specific provision in the Child Act 2001 (Malaysia) (hereinafter, referred to as the CA 2001) that regulates the practice of withholding and withdrawal of life-support treatments in children. Nevertheless, provision of medical care to a child⁵⁴ is considered as part of parental responsibility under CA 2001. Section 17(1)(f) defines that a “child in need” includes a child who needs medical care. Section 31 CA 2001 provides as follows:

‘Any person who, being a person having the care of a child -

- (a) abuses, neglects, abandons or exposes the child in a manner likely to cause him physical or emotional injury or causes or permits him to be so abused, neglected, abandoned or exposed; or*

⁵³ For example, as highlighted by DC McGee, if the aim of a medical treatment is to preserve life, then any treatment that prolongs the life of a person who is in permanent vegetative state is not futile since it helps to preserve the life: DC McGee, AB Weinacker and TA Raffin, ‘The Patient's Response to Medical Futility’ (2000) 160(11) *Archives of Internal Medicine* 1565-6; Anne-Maree Farrell and Edward S Dove, *Mason and McCall Smith's Law and Medical Ethics*, (Oxford University Press, 12th ed, 2023) 517, argues that if medical treatment is withdrawn from a patient who is in permanent vegetative state, it can be said to have been withdrawn owing to not only medical futility but also poor prognosis of quality of life. Hence, the ethical principles of futility and quality of life are very complexed, in reality.

⁵⁴ *Child Act 2001* (Malaysia) defines a child as a person below the age of eighteen years old: at s 2 (*‘CA 2001’*).

(b) *sexually abuses the child or caused or permits him to be so abused,*

Commits an offence and shall on conviction be liable to a fine not exceeding fifty thousand ringgit or to imprisonment for a term not exceeding twenty years or to both.'

The wordings in section 31 above shows that the responsibility to not abuse, neglect or abandon a child is not only limited to parents or lawful guardians; it is also extended by inference to “any person having the care of a child” and this would include the treating medical practitioners. The CA 2001 does not define the word “neglect”. Referring to the case of *R v Sheppard*,⁵⁵ “neglect of a child” is when a person under whom the child is placed for care omits to act or fails to provide the child’s physical needs adequately. Hence, by virtue of sections 17(f) and 31 of the CA 2001, when a medical practitioner under whose care the neonate is being treated, withholds or withdraws medical treatment from the child who is in need of a medical treatment, he or she may be liable for the offence of neglecting the neonate, which is punishable with a fine not more than Ringgit Malaysia fifty thousand or imprisonment of not more than twenty years or both. The discussion below scrutinizes doctors’ legal position based on specific grounds for withdrawal or withholding permitted by the *CPG 2005* to measure adequacy of regulation by the policy and legal framework in Malaysia.

It is hereby submitted that, as highlighted by scholars such as the late Professor Dr Norchaya Talib,⁵⁶ and Fadhlina *et.al.*,⁵⁷ withholding or withdrawing medical treatment on the grounds of medical futility will not render the doctors liable under the law. This is because, when the illness is terminal or fatal and death is inevitable despite provision of medical treatment, the neonate cannot be said to need medical treatment but only requires palliative care. Hence, it is hereby submitted that when medical treatment is withdrawn or withheld on the ground of medical futility, the doctor may be free of liability under section 31 CA 2001, as withdrawing a futile medicine but with continuation of palliative care will be in the best interest of the neonate to avoid prolonged suffering. Hence, it does not amount to neglecting the neonate since the treatment is deemed to be redundant. Withdrawal of medical treatment on medical futility grounds is permitted by the CPG 2005 and is not unlawful under the CA 2001 since futility justifies the need for dignified death. To this extent, the *CPG 2005* and CA 2001 clearly align in regulating withholding and withdrawing medical treatment from severely ill neonates.

Unfortunately, ambiguity arises when withholding or withdrawing medical treatment on the grounds of poor prognosis of quality of life is executed. Even though the *CPG 2005* permits withdrawal of medical treatment from severely ill neonates on the ground of poor prognosis of quality of life, it is arguable that when a neonate has chances of survival but with lower standard of life due to health conditions, withholding or withdrawing medical treatments from such neonates may amount to neglecting the neonate. Terminating provision of medical treatment merely on the ground of severe impairment is challengeable under section 31 CA 2001 since the neonate falls under the category of a child who is in need of medical care as provided under section 17(f) CA 2001 and as defined in the case of *R v Sheppard*,⁵⁸ omission to provide the neonate’s physical needs adequately amounts to neglecting the child. Similarly, withdrawing medical treatment from a severely ill neonate due to reasons of economic burden or lack of social support would also amount to neglecting the neonate under section 31 CA 2001, although it is ethically justifiable under the *CPG 2005*. For these reasons, doctors who decide to

⁵⁵ [1981] AC 394, 404 (*Sheppard*).

⁵⁶ Norchaya Talib, *Euthanasia: A Malaysian Perspective*, (Sweet & Maxwell Asia, 2002) 81-84.

⁵⁷ Fadhlina et al, ‘The Legality of Euthanasia from the Malaysian and Islamic Perspective: An Overview’ (2015) 34(3) *Medicine and Law Journal* 509, 509–532 <<https://irep.iium.edu.my/45974>>.

⁵⁸ *Sheppard* (n 55) 404.

withhold or withdraw medical treatment of severely ill neonates under their care on these grounds may be rendered liable under section 31 CA 2001.

The discussion above shows that even though withholding or withdrawing medical treatment from severely ill neonates on the ground of poor prognosis of quality of life may be ethically justifiable under the *CPG 2005*, it is arguably possible to amount to neglecting the neonate under the CA 2001, when medical treatment is withheld or withdrawn on the said ground. Hence, it can be observed that even though the grounds provided in *CPG 2005* for withholding and withdrawing life-support in neonates are ethically justifiable on the grounds of poor prognosis of quality of life, it may contradict with duty imposed under CA 2001. This leads to ambiguity in the legal position of doctors who decide to withhold or withdraw medical treatment from severely ill neonates and their legal position remains grey when analysed under the Malaysian Penal Code.

B The Penal Code (Act 574) (Malaysia)

As the CA 2001, there is no specific provision in the Penal Code regulating doctor's liability for withholding or withdrawing medical treatment from severely ill neonates.³⁹ However, inference may be drawn from certain relevant provisions codified in the Penal Code to analyze the legal position of doctors who decide to withhold or withdraw medical treatment.

It is hereby submitted that whether withholding or withdrawing medical treatment amounts to an "act" or "omission" is irrelevant for this discussion on the following grounds:

- i. section 32 Penal Code includes illegal omission as part of act;
- ii. section 43 Penal Code defines "illegal" or "unlawful" as everything which is an offence or prohibited by law or provides ground for civil action; and
- iii. section 40 defines offence as a "thing made punishable in the Penal Code".

Hence, referring to discussion under the CA 2001, withholding or withdrawing medical treatment from severely ill neonate on the ground of poor prognosis of quality of life may amount to neglecting the neonate. This would mean, it is "prohibited by the law" as it may be an offence under the CA 2001. Hence, withholding or withdrawing medical treatment may amount to illegal omission which is also part of act. Therefore, whether it amounts to an act or omission is not a crucial argument addressed in this writing. The analysis determining doctors' liability under section 299 and section 300 of the Penal Code will be based on both medical futility and poor prognosis of quality of life grounds.

C Liability for Culpable Homicide under Section 299 Penal Code (Malaysia)

Section 299 Penal Code provides -

"Whoever causes death by doing an act with the intention of causing death, or with the intention of causing such bodily injury as is likely to cause death, or with the knowledge that he is likely by such act to cause death, commits the offence of culpable homicide".

Explanation 1: Deems a person who causes bodily injury to another who is laboring under a disorder, disease, or bodily infirmity and thereby accelerates the death of the other to have caused his death.

³⁹ Section 309A of the *Penal Code 1936* (Malaysia) ('*Penal Code*') provides for the offence of infanticide by mothers who have just delivered their babies. This is not within the scope of this research as this research is only concerning withholding or withdrawal of medical treatment within the hospital settings in Malaysia.

Explanation 2: ...

Explanation 3: Causing the death of a living child, whose any part has been brought forth of the mother's womb, though the child may not have been breathed or been completely born may amount to culpable homicide.

Culpable Homicide under section 299 may be applicable based on intention to cause death or knowledge on the part of the offender that his act is likely to cause death of the victim. Applying the above, when a doctor withholds or withdraws medical treatments from a severely impaired neonate on the ground of poor prognosis of quality of life, the doctor may be liable for culpable homicide under section 299 since the neonate is suffering disorder or disease and the act of withholding or withdrawal of medical treatment may accelerate the child's death and this fact is known to the doctor. However, it must be proven that the neonate would not have died but for the withholding or withdrawal of the medical treatment. The second limb of section 299 in relation to knowledge, is applicable here. Nevertheless, the doctors may not be liable under section 299 Penal Code, if withholding or withdrawing medical treatment is done on the ground of medical futility. This is because:

- a) the neonate's cause of death is not because of the withholding or withdrawing medical treatment but due to the neonate's pre-existing health condition; and
- b) by virtue of section 81 of the Penal Code,⁶⁰ it is justifiable to argue that withholding or withdrawing a futile medical treatment may be excused even though the withholding or withdrawing medical treatment is done with the knowledge that was likely to cause harm provided the doctors are able to prove that the said act or omission was not done with criminal intention to cause harm and in good faith for the purpose of preventing the neonate from prolonged suffering as continuation of the medical treatment would impose burdens of pain which outweighs its benefits.
- c) Under section 89 of the Penal Code, if the act or omission is done in good faith or for the benefit of a person under the age of twelve years old with the consent of the parent or lawful guardian, it is not an offence even though it is done with intention of causing or knowledge that it may cause harm to that person but it must not involve any intentional causing of death or attempt to cause death or grievous hurt. Hence, an act or omission that may result in death or grievous hurt of a child below 12 years old (including neonates) amounts to an excusable provided it is done in good faith (with due care and attention as in section 52) for the benefit of the neonate and with the consent of the guardian or other person having the lawful charge of the neonate.

Hence, it is arguable that when a futile medical treatment is withheld or withdrawn from a severely ill neonate, it is an excusable act or omission even if the neonate's death is accelerated provided it was done in good faith as to not to prolong suffering or burdening treatment for the neonate. It is crucial that the selective-non-treatment was not done with the intention of causing the neonate's death as then it would not be excused under section 89. So, withholding or withdrawal of medical treatment on the ground of medical futility is justifiable under the Penal Code on the ground of necessity and is excusable under section 89 provided the requirements are met (in good faith, not intended to cause the neonate's death, consent of guardian).

⁶⁰ 'Nothing is an offence merely by reason of its being done with the knowledge that it is likely to cause harm, if it be done without any criminal intention to cause harm, and in good faith for the purpose of preventing or avoiding other harm to person or property': *ibid* s 81.

Therefore, doctors will not be liable for culpable homicide under section 299 if a futile medical treatment is withheld or withdrawn from the neonate. At this juncture, there is alignment between the Penal Code and *CPG 2005*.

However, as discussed earlier, doctors may be liable under section 299 for culpable homicide for withholding or withdrawing medical treatment on the grounds of poor prognosis of quality of life. They can be punished with imprisonment which may extend to thirty years (if the act is done intentionally),⁶¹ and fine or if the act is done with knowledge that it is likely to cause death but without any intention to cause death, the punishment will be imprisonment for a term which may extend to ten years or with fine or with both⁶². This shows regulatory gap that exists between Penal Code and *CPG 2005* in dealing with selective-non-treatment of severely ill neonates.

D Liability for Crime of Murder under Section 300 Penal Code (Malaysia)

Section 300 of the Penal Code provides that –

Except in the cases hereinafter excepted, culpable homicide is murder—

- (a) if the act by which the death is caused is done with the intention of causing death;*
- (b) if it is done with the intention of causing such bodily injury as the offender knows to be likely to cause the death of the person to whom the harm is caused;*
- (c) if it is done with the intention of causing bodily injury to any person, and the bodily injury intended to be inflicted is sufficient in the ordinary course of nature to cause death; or*
- (d) if the person committing the act knows that it is so imminently dangerous that it must in all probability cause death, or such bodily injury as is likely to cause death, and commits such act without any excuse for incurring the risk of causing death, or such injury as aforesaid.*

In *Tham Kai Yau & Ors v Public Prosecutor*,⁶³ the judge explained that if the bodily injury inflicted is likely to cause death, it amounts to culpable homicide, but if death is the most probable result, then it is murder under section 300. Hence, the degree of risk that an act or omission poses would determine whether an offence falls under culpable homicide or murder. Applying paragraph (d) of section 300 of the Penal Code, if withholding or withdrawing medical treatment from severely ill neonates is done due to poor prognosis of quality of life and resulted in the neonate's death, the doctor may be liable for an offence under section 300, if he knows that withholding or withdrawing medical treatment from the neonate must in all probability cause the neonate's death and commits the act without any excuse in section 89 of the Penal Code. This is because, the neonate may have survived with the medical treatment even though he or she may be living a poor or lower quality of life compared to other children. For example, a neonate born suffering muscle weakness of a severe degree (spina bifida) may face ambulatory challenges. However, death is not imminent in this case and if the neonate is not provided with the required surgeries or medical treatments that has led to the neonate's death. Hence, withholding or withdrawing any surgeries or medical treatments that may worsen the neonate's health condition and result in the neonate's death may render the doctors liable under section 300 for the offence of murder, which is punishable with death. It would be an uphill task to

⁶¹ Ibid s 304(a).

⁶² Ibid s 304(b).

⁶³ [1977] 1 MLJ 174 [176].

justify it as “excusable murder” under section 89 as well because it is an act or omission which is done knowing to be likely to cause death and not done to prevent death or grievous hurt or to cure any grievous disease or infirmity⁶⁴. Again, a regulatory gap between the Penal Code and *CPG 2005* can be seen as even though not treating the neonate may be ethically justifiable under para 3.1.2 b. *CPG 2005*, it may still render the doctors liable under section 300 Penal Code if withholding or withdrawal is done on the ground of poor prognosis of quality of life.

On the other hand, should medical treatment be withheld or withdrawn from severely ill neonates on the ground of medical futility, it may not amount to murder under section 300 Penal Code since the neonate’s death is not caused by the omission or act of the doctors but by the pre-existing condition of the neonates, which is irreversible. The neonate cannot be said to have not died “but-for” the withholding or withdrawal of the medical treatment in such cases. In addition, withholding or withdrawing futile medical treatment may be excusable under section 89 and can be established to have been done in good faith as provided under section 52 of the Penal Code. Again, similar to section 299, there is no regulatory gap between *CPG 2005* and the Penal Code, if futile medical treatment is withheld or withdrawn from severely ill neonates.

The discussion above shows the gaps that exist to a certain extent between the clinical guidelines and the legal framework in Malaysia in regulating selective-non-treatment of severely ill neonates. Despite the clinical guidelines permitting withholding or withdrawing medical treatments on the grounds of poor prognosis of quality of life, the doctors may still be liable under section 31 CA 2001 and/or sections 299 or 300 Penal Code.

V CONFLICT BETWEEN THE *CPG 2005* AND THE MALAYSIAN LEGAL FRAMEWORK

The discussion above establishes that even though the CA 2001 imposes parental responsibility on parents, it does not define the limit of their duty in providing medical treatment for children in need. In addition, there are conflicts between the policies in reality (*CPG 2005*), the law codified in the CA 2001 and the Malaysian Penal Code when withholding or withdrawal of medical treatment is made based on a prognosis of poor quality of life. Hence, even if medical professionals decide to withhold or withdraw medical treatment in accordance with the guideline provided by the Ministry of Health, they may still be rendered liable for the offence of neglect under the CA 2001 or culpable homicide or murder under the Penal Code. This would hinder medical professionals from practicing a commendable degree of candour in executing the withdrawal. Hence, some doctors who are involved in a selective-non-treatment decision making process do not document in detail the decisions and the process due to fear of attracting liability under the existing legal framework in Malaysia. This is evident from the explanation given by one of the paediatricians interviewed.⁶⁵ He expressed that the conflict between *CPG 2005* and CA 2001 has created fear among the doctors and hinders some of the doctors from being transparent with their decisions in withholding or withdrawing medical treatment from neonates. He added that sometimes, medical treatment is futile, but the parents are at the denial stage and insist on continuation of medical treatment. This puts the doctors in a position where they must convince the parents to withdraw the medical treatment, which may consume hours of meetings and prevent them from using the ventilator for neonates with better opportunities. He wishes that the law would be amended to enable them to be transparent in executing selective-non-treatment without fear of being prosecuted. Proper, detailed documentation for grounds of withdrawal with a commendable degree of honesty and transparency is significant for both present and future medical developments. This could only be achieved if the regulatory gap is bridged. Hence, some significant reforms need to be made to provide clarity to

⁶⁴ Penal Code (n 59) s 89(b).

⁶⁵ Interview with, a paediatrician in one of the public hospitals. (Sivameenambigai a/p Veeriah, Face to face interview, 20.2.2009).

doctors' legal position in this context and clarity in deciding withholding or withdrawal of medical treatment from severely ill neonates. The discussion below proposes reformations to the *CPG 2005*, the CA 2001 and Penal Code to bridge the said gaps highlighted above.

A Steps to Improve the Malaysian CPG 2005

It is evident from the empirical findings for this study that Malaysian hospitals adhere to the doctrine of qualified sanctity of life (medical futility) and quality of life in practicing withholding or withdrawing medical treatment from severely ill neonates. The medical criteria explained by the respondents interviewed for withholding or withdrawing medical treatment clearly show that it is impossible to follow the absolute sanctity of life doctrine. Scarcity of resources may also ethically raise concerns on continuing treatment for fatal neonates. Hence, this paper will not recommend changing the ethical grounds that form basis for deciding to withhold or withdraw medical treatment from neonates. Hence, the grounds provided in the *CPG 2005* to withhold or withdraw medical treatment from severely ill neonates Taking into account the *RCPCH clinical guidelines* and the *Groningen Protocol* of the Netherlands, there are some significant reformations that need to be made to strengthen the *Malaysian CPG 2005*. First, the *CPG 2005* must periodically be reviewed and updated according to the latest medical advancements and developments. Even though it is difficult to define in precision the ethical principles such as "medical futility" and "quality of life" as highlighted in the beginning of this writing, as the UK's *RCPCH clinical guideline*, the *CPG 2005* must contain more detailed explanations that may provide the closest guidance to doctors in deciding to withhold or withdraw medical treatments from severely ill neonates. This is significant to enable the guidelines to set the threshold or standard required of the doctors in this context and can be used in courts for reference. This step will also give confidence to the Malaysian doctors to rely on *CPG 2005* in making their decisions.

Second, in order to give force to *CPG 2005*, three steps may be adopted. First, the *CPG2005* may be sanctioned as a directive by the Malaysian Medical Council so that the breach of its provisions will enable doctors to be subject to disciplinary proceedings under section 29 of the Medical Act 1971. This will significantly assist in bringing uniformity in practicing withholding or withdrawing medical treatment from severely ill neonates in Malaysia as the said clinical guideline will now gain force as MMC's directive.

An additional step to strengthen the force of *CPG 2005* and to promote transparency in practicing withholding or withdrawing medical treatment from severely ill neonates, and the Groningen Protocol of Netherlands may be investigated as a good model. The *CPG 2005* must provide for mandatory recording of details of discussions and the parties involved when decisions are made to withhold or withdraw medical treatment. As provided in the *Groningen Protocol*, the said documents must be sent to the Attorney's office for evaluation. This mechanism will link the hospital level decisions to the Attorney General's office to ensure there is external monitoring of the practice while also promoting transparency and the neonates' best interest. Hence, if the Attorney's office is satisfied that the decisions were made in accordance with the *CPG 2005* in the best interest of the neonates, the doctors will not be prosecuted.

Lastly, the *CPG 2005* must also be amended to include a provision to mandate disputes between parents and doctors to be referred to courts so that decisions made to continue, withhold or withdraw medical treatments by doctors or parents will be sanctioned by the courts. This will provide legal protection to the parties who decide to withhold or withdraw medical treatments, as in the United Kingdom. This will also help to avoid arbitrary decisions at the bedside within hospital settings.

Having seen the steps to be taken to strengthen the *CPG 2005*, the following discussion provides suggestions to bridge the gap between *CPG 2005*, CA 2001 and Penal Code in order to align the clinical guidelines with the existing legal framework to regulate withholding and withdrawing of medical treatment from severely ill neonates in Malaysia.

Steps to Bridge the Malaysian *CPG 2005* with Child Act 2001 (Malaysia) and Penal Code (Malaysia) by L Doyal *et.al*, highlighted that lately the courts have shown interest and respect to medical guidelines in determining continuation, withholding or withdrawal of medical treatment from patients in the hospitals.⁶⁶ Hence, it is important that the guidelines should be in accordance with the existing legal framework. This would also enable the medical professionals in neonatal departments to be guided by proper ethico-legal guidelines and be clear of their legal position when they decide to withhold or withdraw medical treatment from severely ill neonates. This clarity is required to ensure the medical professionals can be transparent in their decisions and document details for future references and medical developments. This is also to ensure the provisions in the CA 2001 and Penal Code are not redundant, in reality.

At this juncture, a lesson could be learned from the USA's experience. Mark Sklansky pointed out that there is a gap between the law in the US and the reality within the hospital settings that practice selective-non-treatment for severely ill or compromised babies. On one hand, the Child Abuse Prevention and Treatment Act (CAPTA) imposes parental responsibility to provide medical treatment and failure to provide medical treatment when the child needs it amounts to child abuse or neglect. Sklansky also highlighted the possibility of parents, doctors and nurses involved in the selective-non-treatment decision and execution to be liable for the offence of murder or manslaughter under the Californian Penal Code despite complying with the criteria set in the Child Abuse Amendment Act of 1984,⁶⁷ since the legal limits for parents' and medical personnel's duty to provide care for infants were not defined.⁶⁸ Hence, Sklansky suggested that amendments should be made to the relevant provisions in CAPTA to exclude expressly withholding or withdrawal of medical treatment from severely ill neonates from amounting to abuse or neglecting the child if the withholding or withdrawal is done in accordance with the medical guidelines.

Looking into the developments in the UK, the Netherlands and suggestions by Sklansky, it is important to have clear Clinical Guidelines that align with the legal framework to provide clarity to the doctors. Again, a similar view was also highlighted by P4, a paediatric in the Paediatric Department in one of the public hospitals. He wishes that there is clarity in law to enable them to execute their duties without being afraid of liabilities under the Malaysian law.

Hence, this writing proposes four significant steps as follows to fill the gap between the *CPG 2005*, CA 2001 and Penal Code:

- i. To insert an exclusion provision in the CA 2001 which may limit parental responsibilities in providing medical treatment for severely ill neonates in Malaysia. Section 17 (1) (f) CA 2001 which defines "a child in need of care," should be amended to exclude expressly children or neonates whose medical treatments are justified to be withdrawn according to the grounds and procedures under *CPG 2005*. This will exclude the medical professionals or parents from being liable under section 31 CA 2001 for the offence of neglecting

⁶⁶ L Doyal and VF Larcher, 'Drafting guidelines for the withholding or withdrawing of life sustaining treatment in critically ill children and neonates' (2000) 83(1) *Arch Dis Child Fetal Neonatal Ed* 60, 60–63, <<http://fn.bmj.com/>>.

⁶⁷ This Act excludes attracting liability for withdrawal of medical treatment from certain categories of babies such as infant with chronic and irreversible comatose, babies for whom medical treatment would be futile or merely prolonging dying and futile in survival of the infant.

⁶⁸ Mark Sklansky, 'Neonatal euthanasia: moral considerations and criminal liability' (2001) 27(5) *Journal of Medical Ethics* 5, 5–11 <<https://pubmed.ncbi.nlm.nih.gov/11233379/>>.

the baby so long as they have complied with the grounds under *CPG 2005*. Hence, the said section should be amended to include the following provision:

Section 17(1)(f): “A child is in need of care and protection if –

(f) the child needs to be examined, investigated or treated-

- (i) for the purpose of restoring or preserving his health; and*
- (ii) his parent or guardian neglects or refuses to have him so examined, investigated, or treated;”*

but this does not include children whose medical treatment are withheld or withdrawn in accordance with the Clinical Practice Guidelines in relation to Withholding and Withdrawing of Life Support in Children 2005 issued by Ministry of Health, Malaysia [emphasis added to show insertion].

- ii. Section 31 CA 2001 should also include an exclusion provision to exclude doctors who decide to withhold or withdraw medical treatment from being liable for neglecting children so long as they have complied with all the steps required in the Malaysian CPG 2005 and affirmed by the Attorney’s office to be free of reasons to be prosecuted. Hence, the section should read as follows:

Section 31 CA 2001:

(1) Any person, who, being a person having the care of a child –

(a) abuses, neglects, abandons or exposes the child or acts negligently in a manner likely to cause him physical or emotional injury or causes or permits him to be so abused, neglected, abandoned or exposed; or

(b) sexually abuses the child or causes or permits him to be so abused, commits an offence and shall on conviction be liable to a fine not exceeding fifty thousand ringgit or to imprisonment for a term not exceeding twenty years or to both.

The phrase “neglects, abandons or exposes the child or acts negligently...” in this section shall not be construed to amount to neglecting or abandoning or exposing the child or acting negligently in the context of withholding or withdrawing medical treatment from children executed in accordance with the Clinical Practice Guidelines in relation to Withholding and Withdrawing of Life Support in Children 2005 issued by Ministry of Health, Malaysia [emphasis added to show insertion].

- iii. Section 89 Penal Code to be amended to insert provision as follows rendering withholding or withdrawing of medical treatment in accordance with CPG 2005 as “excusable” act or omission.

Act done in good faith for the benefit of a child or person of unsound mind, by or by consent of guardian

89. *Nothing, which is done in good faith for the benefit of a person under twelve years of age, or of unsound mind, by or by consent, either express or implied, of the guardian or other person having lawful charge of that person, including withholding and withdrawing medical treatment in accordance with the Clinical Practice Guidelines in relation to Withholding and Withdrawing of Life Support in Children 2005 issued by Ministry of Health, Malaysia [emphasis added to show insertion], is an offence by reason of any harm which it may cause, or be intended by the doer to cause, or be known by the doer to be likely to cause, to that person...*

iv. Section 299 Penal Code to be amended as follows:

Culpable homicide

299. *Whoever causes death by doing an act with the intention of causing death, or with the intention of causing such bodily injury as is likely to cause death, or with the knowledge that he is likely by such act to cause death, commits the offence of culpable homicide.*

The provision above is subject to excuse provided in section 89 of this Code.

v. Section 300 Penal Code to be amended as follows:

Murder

300. *Subject to section 89, except in the cases hereinafter excepted, culpable homicide is murder-*

- (a) if the act by which the death is caused is done with the intention of causing death;*
- (b) if it is done with the intention of causing such bodily injury as the offender knows to be likely to cause the death of the person to whom the harm is caused;*
- (c) if it is done with the intention of causing bodily injury to any person, and the bodily injury intended to be inflicted is sufficient in the ordinary course of nature to cause death; or*
- (d) if the person committing the act knows that it is so imminently dangerous that it must in all probability cause death, or such bodily injury as is likely to cause death, and commits such act without any excuse for incurring the risk of causing death, or such injury as aforesaid.*

The reformations proposed above are vital to align the practice of withholding or withdrawing medical treatment with *CPG 2005*, *CA 2001* and the Malaysian Penal Code. It will also protect

doctors who decide in the best interest of severely ill neonates while promoting the best interest of the latter.

VI CONCLUSION

The findings in this study show that withholding or withdrawing of medical treatment from severely impaired neonates are being practiced within hospital settings in Malaysia. Even though life is considered sacred, the practice is based on qualified sanctity of life which sanctions withholding or withdrawal on the ground of medical futility. It is also based on the quality of life principle which enables termination of treatment if the outcome of the treatment will render the neonate to lead a life of poor quality. The *CPG 2005* permits withholding or withdrawal of medical treatment from children on these grounds. However, the necessity to regulate the practice efficiently is evident from the variation in practice amongst the doctors. However, this study establishes that there are gaps between the practice of withholding and withdrawing medical treatment from severely ill neonates, the clinical guidelines (*CPG 2005*) and the existing Malaysian legal framework which requires rectification. The rectification's aim is to provide clarity as to the doctors' legal position when they decide to withhold or withdraw medical treatment from severely ill neonates, to ensure that the *CPG 2005* is periodically updated and reviewed so as to at par with the latest medical developments and to be a document that is able to set the standard of care required of the doctors in this practice. The *CPG 2005* must also be given force via MMC and the Medical Act 1971. This is to ensure that the doctors refer to the guideline and uniformity in practice is achieved amongst the hospitals in deciding to continue, withhold or withdraw medical treatment from severely ill neonates to avoid inequality and to protect the best interest of the neonates. Hence, tidying up and scrutinizing the provisions in the *CPG 2005* with detailed elaboration as the *RCPCCH guidelines* and with some mandatory steps to be taken by the doctors such as documenting and reporting the decisions as provided in *Groningen Protocol* are the vital steps to be taken in bridging the regulatory gap. Linking the Attorney General's office to the *CPG 2005* provisions requiring mandatory reporting of details of discussion and decisions made by the medical team when deciding to withhold or withdraw medical treatment from severely ill neonates will promote transparency while protecting the neonates' best interests. In addition, including courts as a platform in the event of confusion in deciding to withhold or withdraw medical treatment will also provide protection to the doctors from possible legal prosecutions under the Child Act 2001 and Malaysian Penal Code while also promoting the neonates' best interests. All the reformation steps proposed in this study are strongly hoped to be able to bridge the regulatory gap identified in the practice of withholding and withdrawing medical treatment from severely ill neonates in Malaysia. It is hereby recommended that the feasibility of involving the Attorney General's office in this matter in Malaysia and how this mechanism operates in the Netherlands may be a direction for future research.