

**University of Alberta**

**Attitudes and Opinions of Pediatric Physicians Regarding  
Decisions to Withdraw or Withhold Medically-Provided  
Hydration or Nutrition**

by

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## **Dedication**

In memory of Joshua. His courageous fight inspired our family in ways we never imagined.

## **Abstract**

Deciding to forego intravenous hydration (IH) and medically-provided nutrition (MPN) in pediatric patients remains controversial. Minimal published research exists that explores the attitudes and approaches of pediatricians who are making these decisions.

This survey explored attitudes and opinions of pediatricians that influence decisions to forego IH & MPN in children.

Sixty Canadian pediatricians responded amongst whom 49 had previous experience with foregoing IH & MPN. Respondents felt that IH & MPN were medical treatments, withdrawal was ethically permissible, and that these should be addressed separately from discussions about withdrawal of other life-sustaining therapies. Fewer respondents felt IH & MPN were ethically equivalent to other life-sustaining therapies. Most respondents felt greater discomfort withdrawing IH & MPN. Own emotional comfort was less influential in experienced pediatricians compared to pediatricians without experience.

The approach of experienced pediatricians deserves further study to help refine current guidelines and education of new pediatricians who may face these issues.

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## List of Symbols and Abbreviations

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AAP – American Academy of Pediatrics

AHN – Artificial Hydration and Nutrition

CABSI – Catheter-Associated Blood Stream Infection

CAPTA – Child Abuse Prevention and Treatment Act

CNS – Central Nervous System

CPR – Cardiopulmonary Resuscitation

CPS – Canadian Pediatric Society

EN – Enteral Nutrition

HCP – Health Care Provider

H/O/P – Hematology, Oncology and Palliative Care

IBM – International Business Machines

ICU – Intensive Care Unit

IF – Intestinal Failure

IFALD – Intestinal Failure-Associated Liver Disease

IH – Intravenous Hydration

IV - Intravenous

LST – Life-sustaining Therapy

MPN – Medically Provided Nutrition

NEC – Necrotizing Enterocolitis

NICU – Neonatal Intensive Care

NG – Nasogastric

PCCM – Pediatric Critical Care Medicine

PN – Parenteral Nutrition

PVS – Permanent Vegetative State

SBS – Short Bowel Syndrome

SCCM – Society of Critical Care Medicine

US – United States

URL – Uniform Resource Locator

## Introduction

The decision to withdraw or withhold intravenous hydration (IH) and medically provided nutrition (MPN) in an infant or child with a medical condition that makes medically provided feeding difficult or undesirable, is difficult and complicated. However pediatric physicians practicing in a variety of disciplines (General Pediatrics, Hematology/Oncology/Palliative Care (H/O/P), Neonatal Intensive Care (NICU), Neurology, Pediatric Critical Care Medicine (PCCM)), and who care for these individuals, must occasionally address this issue and the profound moral and ethical issues that emerge (2-5).

Most of these moral and ethical issues center on the perception of the role of hydration and nutrition. Are IH and MPN medical treatments or basic human needs (all children should be fed)? Is withdrawing or withholding IH and MPN perceived as “starving the patient to death” (passive euthanasia)? Conversely, is the child being “force-fed” thus prolonging the dying process? Do IH and MPN improve the quality of remaining life or do they increase suffering? Finally, who raises the issue? Should discussion about withdrawal or withholding of IH and MPN be physician-initiated, or should the medical team wait for the child’s parents to bring up the issue?

Intravenous hydration and medically provided nutrition are commonly considered medically and ethically appropriate standards of care. It is generally assumed that nutrition and fluids should always be offered if the child can consume beneficial amounts by mouth or parenterally if indicated (3). But in certain circumstances (e.g. permanent vegetative state (PVS),

neurologic devastation, total intestinal failure, proximate death from any cause), IH and MPN may prolong the dying process. Near the end of life, medically provided fluids may cause pulmonary edema, excessive respiratory and oral secretions, and considerable discomfort (3,6-8).

Intravenous hydration and medically provided nutrition can be ethically and clinically considered as common medical care, rather than as a universal human requirement (3,6,7,9). However the characteristics of the intervention are not sufficient to justify either withholding or providing a treatment (3). One must also consider whether this treatment is likely to benefit the patient sufficiently to make it worthwhile to endure the associated treatment burden (3,10). Finally, the medical team needs to discuss with the family what constitutes a valued life – or, what is viewed as prolonging death. Overall, the final decision is complex and ultimately depends on the child's diagnosis and prognosis, the views of the parents on the role of IH and MPN and their effects on their child's life, the views of the child (if able to express), and the views and experiences of members of the child's medical team.

### **Pediatric guidelines and research**

While most institutions have guidelines for provision of medically provided nutrition and hydration in adult patients receiving palliative care (11), specific pediatric or neonatal guidelines have only recently been developed by the American Academy of Pediatrics (AAP) and the Canadian Pediatric Society (CPS)(6,12). These documents contain a comprehensive review of the ethical issues, legal aspects, existing controversies, and specific situations where withdrawal or withholding of IH and MPN may be encountered (6,12). Nevertheless, they provide only a theoretical framework and do not address the reality of a specific situation and its effects on the child, parents, extended family, and

healthcare providers. Guidelines on forgoing any life-sustaining medical treatment in children also exist, but they do not address in any detail the specific issues regarding withholding or withdrawal of medically provided nutrition and hydration (7,8,13,14).

Pediatric-specific research in this area is lacking and only provides evidence that most practitioners approach the issue of life-sustaining therapy (LST) – not specifically withdrawing or withholding IH and MPN – in a “trial and error” fashion (15), and are guided more by individual values (16) despite rating their knowledge of the ethical issues as high (1). A survey evaluating only withdrawing or withholding IH and MPN has not been published previously.

### **Why it is important to identify determinants of the decision to withhold or withdraw medically provided nutrition and hydration**

In end-of-life situations, the child’s expected outcome, quality of life, and best interests are at the forefront of all care decisions. Medically provided hydration and nutrition must be included in the decision-making process regarding the child’s goals of care as moral and ethical arguments exist justifying them as medical therapies with benefits and harms. Ultimately, a final consensus must occur between the medical team and the child’s family when deciding upon the appropriateness of proposed medical intervention. Foregoing IH and MPN is a difficult and complex decision almost always accompanied by a high level of emotional discomfort. The symbolism ascribed to feeding utterly dependent children is powerful. This may reinforce the assumption that withholding or withdrawing medically provided nutrition and hydration is wrong (3,17,18).

## **Contribution of this thesis**

This thesis seeks to identify the attitudes and approaches of practitioners regarding withholding or withdrawing IH and MPN. This thesis describes the development and implementation of a survey of Canadian pediatric practitioners that explores an aspect of this issue not previously reported. Identifying these attitudes and approaches is imperative because the complexity of these situations can lead to widely varied approaches, some perhaps less justifiable than others. By identifying those patient and practitioner factors that influence the final decision, I hope to gain a better understanding of the extent of variation in approaches. This may help improve existing guidelines.

## II

### Review of the Literature

#### Structure of the Review

This literature review explores several aspects of withdrawing or withholding IH and MPN in children. First, important key terms used in this thesis will be defined. Second, moral and ethical issues that have emerged as a result of the clinical processes of deciding and implementing withdrawal or withholding of IH and MPN will be reviewed. These will focus on:

- How IH and MPN are different than “normal” feeding,
- Are IH and MPN medical treatments?
- Is withdrawal of these treatments akin to starving a child?
- What clinical situations exist where the burdens of continuing IH and MPN may outweigh their benefits?
- Why are withdrawing or withholding IH and MPN uncomfortable?
- Is there an obligation for physicians to bring up the option of withdrawing or withholding IH and MPN, or should the issue only be addressed if the parents or guardians bring it up first?

The next section of the literature review briefly explores legal aspects of foregoing these specific therapies. I then review the key perspectives arising from the adult literature that have influenced the development of pediatric guidelines. The final section reviews recently published pediatric guidelines and the small number of publications that have researched these issues in pediatrics.

## Definitions

*Intravenous Hydration (IH)* – fluid, contained in an intravenous bag, that is administered to a person through a catheter placed in a vein. In select patients, IH can be given through a similar catheter placed under the skin (dermoclysis). It provides a means of hydrating a person if they are unable to maintain hydration by drinking.

*Medically Provided Nutrition (MPN)* – a specially constructed formulation of important and essential nutrients, proteins, lipids, and carbohydrates that can be administered to a person through several means (see below). MPN is sometimes referred to as AHN (artificial hydration and nutrition). It provides a means of nourishing a person if they are unable to adequately take enough nutrients and calories by mouth.

*Enteral Nutrition (EN)* – the administration of MPN via a special tube placed in the stomach from above (nasogastric (NG) tube; which is inserted into the nose and travels down the posterior pharynx to the esophagus ending at the stomach) or through a direct surgical connection from the surface of the upper abdomen into the stomach (gastrostomy tube).

*Parenteral Nutrition (PN)* – the administration of MPN through a catheter placed in a vein. PN provides a means of delivering adequate nutrients and calories to a person if they are unable to adequately feed by mouth and/or unable to absorb such nutrients and calories through their digestive system.

## **Moral and Ethical Issues**

The issue of withdrawing or withholding IH and MPN has undergone a long, thorough, and heated ethical “evolution” over the past several decades. Prominent public and legal proceedings both in adults (19,20) and children (21-23) have generated numerous scholarly publications both supporting and opposing the right to forego these specific therapies (24-27). This debate has resulted in continued examination of the moral and ethical issues surrounding these difficult and controversial decisions. Major professional societies have subsequently developed position statements on foregoing IH and MPN (6,12).

In the 1980’s, initial academic exploration of the issues surrounding withdrawal or withholding of IH and MPN resulted in uneasy support throughout the medical profession, government, and the courts. While a more permissible opinion emerged with respect to the withdrawal of IH and MPN in seriously ill adults in specific circumstances (24,28-31), an attitude of opposition persisted for children (32,33). Official policy from the AAP at that time did not specifically address withdrawal of IH and MPN but rather endorsed withdrawal of life-sustaining treatment from children who are:

“so impaired that treatment will serve only to maintain biologic functions (34).”

The Surgeon General of the United States at the time, C. Everett Koop, held a condemning view of withdrawal of MPN stating it to be “necessary for survival” and describing withdrawal of nutrition as “starving a child to death (32).” He also believed this practice “constitutes infanticide, leading to moral erosion that that may eventually undermine the care of all patients (32).”



The adult and pediatric disconnect in this decision was further magnified in conflicting publications from the United States Government. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (24) endorsed withholding MPN from adults who are permanently unconscious, while the U. S. Department of Health and Human Services consistently expressed disapproval of withholding nutrition from infants, even in situations where other lifesaving measures may be discontinued (22,23,35,36). This led to amendment of the Child Abuse Prevention and Treatment Act (CAPTA)(27) in 1984, mandating withdrawal of federal funding from state child protective services agencies if they did not have mechanisms for reporting and investigating:

“...medical neglect, including instances of the withholding of medically indicated treatment (including appropriate nutrition, hydration and medication) from disabled infants with life-threatening conditions (6,25,27).”

The CAPTA then stated that in 3 specific circumstances, medical treatment need not be provided “other than appropriate nutrition, hydration, and medication” based on the physicians’ reasonable judgment:

1. The infant is chronically and irreversibly comatose;
2. The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or would be “futile” in terms of the infant’s survival;
3. The treatment would be “virtually futile” and “inhumane.”

While the language of the CAPTA seems to endorse the provision of appropriate fluids and nutrition in most pediatric cases, this was not the purpose of the CAPTA amendment. The CAPTA statement was created to make sure states had reporting mechanisms in place in order to receive funding for child abuse prevention programs, and was not intended to be a standard of physician or institutional liability (3,37). The AAP argues that the CAPTA report aimed to define the appropriate use of medically, provided hydration and nutrition, namely, when they serve the interests of the child and when they are expected to offer a level of benefit to the child that exceeds the potential burden to the child.

Although these publications generated conflict and controversy, they also resulted in a deeper examination of the issues surrounding withdrawal and withholding of IH and MPN. Further academic discussion centered on several key issues that will be discussed in the following sections:

- Are IH and MPN medical treatments or basic human needs?
- Which clinical situations deserve consideration of withdrawal or withholding of IH and MPN?
- What aspects of withdrawal or withholding of IH and MPN are emotionally uncomfortable to clinicians?
- Who should bring up the issue of withdrawing or withholding IH and MPN first? The physician or the parents?

### *Are IH and MPN Medical Treatments?*

This question forms the fundamental basis of both the ethical and legal justifications for considering withdrawal or withholding of IH and MPN and has been comprehensively reviewed in the AAP Bioethics Committee publication by Diekema and Botkin (6) and in a review by Nelson et. al. (3). Both publications appropriately emphasize how IH and MPN will

benefit or burden the child as being central to the decision, not on whether it is or is not a medical therapy. Their major points, with supporting references, are summarized below.

The main argument against IH and MPN being medical therapies similar to other LST is that they represent basic forms of care that can never be withdrawn or withheld (3,10,18,38,39). A well-fed child is conveyed as a sign of good parenting in many societies (40,41). Feeding a child is an important nurturing aspect between a parent and a child (42), and society attaches many social and cultural meanings to child nurturing and to food. Feeding is used to meet the child's nutritional needs, to demonstrate love, and to reward and punish (40,41).

What is presented well in the AAP review is that, while all these social aspects of feeding are important and exist in all societies, MPN is different. It does not lead to the pleasure gained from chewing and tasting food, or the enjoyment gained from the social aspects of sharing food or participating in mealtime. Some children receiving MPN also do not experience hunger or thirst, and have different nurturing needs that cannot be accomplished by MPN. Additionally, IH and MPN require medical intervention. There is a requirement for feeding tubes, special feeding pumps, special formula and sometimes, surgical procedures to be integrated so that nutrition can be provided. Adverse events and complications (reported as high as 76% (43,44)) need to be monitored and can lead to discomfort due to dyspnea, fluid overload, edema, skin breakdown, infection, fluid and electrolyte imbalance, pain, thrombosis, organ damage, and nutritional excess or deficiencies (6).

These requirements and adverse effects of MPN also serve to dispel the misperception that feeding procedures are not invasive, nor painful and risky like other LST such as ventilation (3).

Establishing IH and MPN as medical treatments is important because it allows these interventions to have the same consideration as other LST; that is, IH and MPN may or may not be appropriate depending on the goals of treatment (45). More importantly, it shifts the focus away from the medical treatment attributes of IH and MPN and allows examination of whether they are likely to provide the child benefits that are sufficient to make it worthwhile to endure the burdens that accompany the treatment (3). It also allows parents and physicians to justify its withdrawal or withholding under similar conditions to other LST (6,14):

1. A competent person has refused the intervention
2. A Substitute Decision Maker, in consultation with a physician, having concluded that the burdens of the intervention exceed its potential benefit may also decline the intervention.

Applying these conditions allows further exploration of specific clinical situations where withdrawal or withholding of IH and MPN may be considered.

*Which clinical situations deserve exploration of withdrawal or withholding of IH and MPN?*

Before exploration of specific clinical situations can occur, it is important to emphasize that withdrawal or withholding of IH and MPN in these (or other similar) situations is morally *optional*. That is, they *may* be foregone, not *should* be foregone. The medical situation, and the attendant risks and benefits of medically provided hydration and nutrition is the most important element of the decision. When medically sanctioned, parents should be granted wide discretion. Their ethical, religious, and cultural beliefs should be taken into account; and the medical plan should conform to the values and choices of the patient and family (6,14). The family's preferences

should be supported, and even if they appreciate the ethical permissibility of withdrawal or withholding IH and MPN, they may still not feel comfortable with the choice (2,3). It is also important to consider that in the overwhelming majority of situations, IH and MPN are ethically appropriate and should usually be offered if the child is unable to consume beneficial amounts by mouth (3).

### *Permanent Vegetative State*

PVS is defined as “a clinical condition of complete unawareness of the self and sleep-wake cycles with either complete or partial preservation of hypothalamic and brainstem autonomic functions” (46,47). The Multi-Society Task Force on PVS recommends that only the term permanent be used over persistent to imply an irreversible state. The Task Force judges permanence in children to be after 12 months for a traumatic brain injury and 3 months for a non-traumatic injury (47). These children have complete lack of awareness of themselves and the environment, are incapable of experiencing pleasure or suffering, and do not consciously experience any benefit from continued existence (6). This state also results in an inability to feed orally. Artificial feeding in this scenario poses risk of aspiration. As a result, both Diekema and Botkin, and Nelson et. al. conclude that MPN which does not provide benefit is inconsistent with the child’s best interests, and that forgoing it is therefore within the scope of parental decision-making authority (3,6). Nelson et. al. further emphasize that indefinite treatment of such a child can have debilitating effects on family members (3).

### *Other congenital or acquired neurological impairment*

Congenital central nervous system (CNS) malformations such as anencephaly (complete absence of the cerebral cortex; thus unable to develop conscious awareness (48)) and hydranencephaly (minimal cerebral cortical tissue, may show limited awareness of environment and purposeful activity; usually remain in PVS (49)) result in an inability to suck and are formally considered part of PVS (47). As a result, they are subject to similar discussions about withdrawal or withholding IH and MPN as other PVS states. Other congenital and acquired CNS injury states such as profound perinatal asphyxia, degenerative and metabolic brain disorders, and near-drowning may not formally fulfill the criteria for PVS due to time or neurodevelopmental considerations but these constraints may not need confirmation to warrant discussion on decisions about LST (3,47). Nelson et. al. conclude that in these situations it is legitimate to decide that no treatment (including IH and MPN) is appropriate based on the following considerations (3):

1. The unacceptability of the child's expected outcome and potential to relate to the environment (i.e. child so damaged as to have an unacceptable future)
2. The anticipated treatment burden and harm to the child
3. The physicians' and parents' willingness to gamble with the choice either for or against treatment

### *Intestinal Failure*

Intestinal failure (IF) is defined as a total reduction in functional gastrointestinal mass below the minimum needed to digest and absorb fluids and nutrients required to sustain appropriate growth and development (50-55). In children, the most common cause of intestinal failure is short bowel syndrome (SBS) due primarily to necrotizing

enterocolitis (NEC) and gastroschisis (50,51,56,57), The average reported incidence of IF in neonates weighing <1500 grams is 7/1000 (56). These patients, due to their limited ability to feed orally or enterally, are partially or totally dependent on PN or IH (51).

Dependence on PN introduces new problems for the child as severe and chronic complications may arise; these include central venous catheter infections, PN cholestasis and liver failure, and bacterial overgrowth syndrome (50,51,58-62). Intestinal transplant, while continuing to show improved outcome (63-65), remains a complex, high-risk procedure with its own post-transplant adverse effects especially if a concomitant liver transplant is required (66). Many infants die on the waiting list due to shortage of donor organs, leading to a high overall mortality of all eligible transplant candidates. Other barriers to transplant are lack of any further central venous access sites by which to be able to provide PN (3,67).

For all these reasons, withdrawal of IH and MPN, although emotionally difficult, may be acceptable when the potential burdens to the child may outweigh the benefits (3,67). Given the high chance of morbidity and mortality at present, some parents decide against embarking on long-term PN as a bridge to potential transplant, and elect to allow the baby a comfortable death.

### *Proximate Death*

Some children, in the final stages of the dying process, are unable or unwilling to take oral fluids or food, and provision of IH and MPN may actually cause discomfort due to nausea, vomiting, increased secretions, and coughing. That is, when the burdens of IH and MPN are likely to outweigh the benefits, they can be withdrawn or withheld. Diekema and Botkin discuss these situations in a general sense and focus on the

important aspects of this stage of illness (6). The process of dying may also be prolonged by provision of IH and MPN (42). As well, the provision of IH and MPN may add extra burdens on the child and family through increased need for ongoing hospitalization and monitoring; this may be incongruent with the family's goals of care (6).

*What aspects of withdrawal or withholding of IH and MPN are uncomfortable?*

Among professional groups, ethicists, and the courts, there has been acceptance of withdrawing or withholding IH and MPN. This has evolved over the past several decades as they have been regarded more as medical therapies that can be justifiably withdrawn or withheld depending on the best interests of the child. Yet, there is still palpable discomfort among pediatric caregivers to forego these interventions in situations where the option of withdrawal or withholding exists (1,3,68,69).

The specific research findings from the referenced observational studies will be explored in more detail in the Pediatric Research section. The remainder of this section will focus on the specific controversies that may contribute to physician reluctance and discomfort. Details of the ethical arguments are taken from both the comprehensive reviews by Nelson et. al. and Diekema and Botkin as well from an interesting, personal account by Mirae, a medical student who confronted this issue as a parent of a child with a severe neonatal hypoxic-ischemic brain injury (2,3,6).

Both Nelson et. al. and Diekema and Botkin highlight that physician discomfort may arise due to the symbolic significance of food and feeding a child. Nelson et. al. go on to argue that labeling the withdrawal or withholding of MPN as cruel deprivation is “ethically shortsighted (3).” It is definitely wrong to withhold food from otherwise healthy children, and even



most sick children, but the situation is different if the child's life prospects are profoundly diminished and will not derive any benefit from MPN (3,5).

A second issue that drives physician reluctance is the argument that IH and MPN should always be provided because children cannot independently make their own decisions, and cannot make known their values or treatment wishes. This issue is elegantly discussed and diminished by Nelson et. al. with supporting documentation from a 1988 Conservatorship ruling in California (3,70). While this loss of autonomy for the child can make a physician hesitant, Nelson et. al. argue that it also makes children "passive objects of medical technology" when in reality they "actually have the right to have appropriate medical decisions made in their best interests. (3,70)" This argument is further illustrated by the conservatorship ruling which provided 2 important statements (70):

"Life is prolonged because it is possible, not because anyone purporting to speak for [them] has decided that this is the best or wisest course."

"The problem is not to preserve life under all circumstances but to make the right decisions."

Although these statements are definitive and again focus on the child's best interest, the discomfort remains for physicians and parents. Mirae illustrates this point well, stating that it is one matter to theoretically discuss the issue, but an entirely different matter to actually implement it. There will always be a fair amount of subjectivity in each situation. This was highlighted in a letter responding to Mirae's publication (71,72) and in the AAP publication by Diekema and Botkin both of which emphasized that parents should be granted wide discretion. Mirae also advocated for wide discretion, although she chose not to forego MPN (2):

“However, at times, every alternative is grim, and in these cases we should not bar others from deciding to withhold artificial nutrition if it appears to be the best option for their child.”

One final area of controversy that contributes to physician discomfort is described by Nelson et. al. as a “deeply embedded reluctance to give up on young patients (3).” This is likely fueled by diagnostic and prognostic uncertainty, and the resilience of children. Therefore, they are given more “chances” and caregivers are more willing to impose greater burdens on them (3). Nelson et. al. argue that age is not an ethically acceptable basis to decide when to forego treatment. Mirae further echoes these arguments stating that when an illness is terminal, age is irrelevant (2). She also goes on to emphasize that because of prognostic uncertainty, more time may be required to establish a secure prognosis, so allowing time to fully consider all options for care is reasonable. This is further illustrated in the AAP publication by Diekema and Botkin who encourage ample time be taken because, 1) most situations are not urgent in nature, and 2) this allows the family to fully consider all the options and ramifications of available treatment pathways and consult with appropriate people (extended family, clergy, other medical opinion, ethics) to aid them in their decision (6).

*Who should bring up withdrawal or withholding of IH and MPN?*

The final major ethical issue centers on whether physicians are obligated to inform parents of the option of foregoing IH or MPN. This was reviewed in detail by Levi et. al. (4) who highlights several important ethical aspects which confirm that physicians do have an obligation to inform families of this option:

1. IH and MPN are medical treatments.
2. There are professional norms regarding decision-making and informed consent to medical treatment.
3. Being uncomfortable about providing or foregoing a particular medical treatment does not mitigate the physician's responsibility.

These aspects are further corroborated by the AAP guideline on LST (14) which states that the physician:

“Should present available options for the family to consider all available information.”

“Should be careful to separate personal views from medical/legal/moral standards of care”

“Cannot withhold information for fear of upsetting the decision-maker.”

This guideline further states that physicians should arrange proper care if they decide not to be involved.

### **Legal Aspects**

Physicians involved in pediatric care where withdrawal or withholding of IH and MPN is being considered may fear legal reprisal. There is an apprehension based on the publicity garnered from lawsuits and press coverage of these situations, that the legal system considers withdrawal or withholding of IH and MPN illegal. This fear is unfounded and is corroborated by numerous judicial decisions described below.

Four decisions involved children with PVS in which the parents supported the withdrawal of MPN (73,74). Major rulings from all four cases were similar and were summarized in Nelson et. al. (3):

1. The incompetent child had the right to refuse treatment which could be exercised by the parents or guardians and a court.
2. No state interest outweighed this right.
3. Medical ethics did not prohibit stopping MPN.
4. It was in the child's best interest to authorize withdrawal of nutrition and hydration and allow him/her to die peacefully, painlessly and with dignity.

Four additional decisions involved never competent persons that were considered equivalent to children in that they were never able to articulate their own desires about receiving medical treatment (75-78). Summarizing the rulings again reveals major themes that justify the withdrawal or withholding of IH and MPN in similar situations involving children (3):

1. The decision to withdraw MPN properly belongs to the patient's family; not strangers or the government (75).
2. MPN is a medical treatment that can be refused (75-78) and in three appellate court rulings is "as optional as a ventilator (79,80)" if the parent determines that it is no longer beneficial to the child.
3. No objective distinction can be made between MPN and other medical treatment (75).
4. Incompetency should not result in the denial of the right of being free from medical interventions (75). An incompetent person deserves to have someone evaluate the propriety of medical interventions (3).

Overall, these legal rulings affirm that withdrawal or withholding of IH and MPN can occur in children in select situations. These rulings also agree that many of the same reasons for withdrawal or withholding IH and MPN in adults also apply to children (3).

### **Perspectives from the Adult Experience**

Experience with the withdrawal or withholding of IH and MPN in adults started to accrue in the late 1970's when several legal cases formed the foundation to guide ethical decision-making about care at the end of life (81-83). Those principles have continued to evolve, have withstood legal challenges (84), and have allowed for the natural extension of these principles to children in similar end-of-life situations.

Adult studies provide additional understanding of the process of death when IH and MPN are withdrawn or withheld. Studies of patients who have had feeding withdrawn show that very little discomfort occurs (85-89), with the cause of death being progressive dehydration and not starvation (20). The proposed mechanism for decreased suffering is the sedative effect of dehydration due to accumulation of ketones and endorphins (44,88). In a survey of hospice nurses from Oregon, when asked about the quality of death of patients who voluntarily refused food and fluids, rated the quality of death as "good" (score of 8 on a 9-point scale)(90). Finally, there is a suggestion that death from "old age" is actually due to a gradual cessation of eating and drinking (91).

Diekema and Botkin highlighted the final interesting adult perspective in their AAP publication (6), in which they examine application of the "reasonable person" standard to withdrawal or withholding of IH and MPN in PVS. Several studies have looked at the preferences of Americans, asking the public if they would want IH and MPN if they were, themselves,

in a PVS (92-96). The majority of respondents indicated that they would not want IH and MPN. Additional surveys also indicated that most agree that surrogate decision-makers are permitted on their behalf to forego these interventions (97,98).

### **Appraisal of Pediatric Guidelines**

Two relevant publications exist from the AAP. The first guideline, *“Guidelines on forgoing life-sustaining medical treatment,”* published in 1994, gives an overview and guide to foregoing life-sustaining medical treatment (14). While this guideline does not explore withdrawal or withholding of IH and MPN in depth, it does mention that they are medical interventions that can be withdrawn or withheld. These guidelines also state that decisions to forego LST apply to each specific intervention. The medical plan must conform to the values and choices of the patient and family, the benefits and burdens of each LST must be explored, and that the needs of the child must remain primary.

The second publication, *“Forgoing Medically Provided Nutrition and Hydration in Children,”* by Diekema and Botkin (6) expands on the basic principles defined in the 1994 guideline and specifically looks at withdrawal or withholding of IH and MPN. This publication has many strengths providing a practical framework of the issue of foregoing IH and MPN in children that encompasses relevant and important ethical and legal aspects. It recognizes the controversies that exist in these situations and addresses them. Specific situations in which withdrawal or withholding of IH and MPN can be considered are provided. This guideline acknowledges the difficulties with withdrawal or withholding of IH and MPN in less well-defined situations. Although comprehensive, this publication does have limitations. Its primary focus is the theoretical framework and exploration of the ethics behind withdrawal or withholding

of IH and MPN. There is no significant discussion about being in real clinical situations, nor are there perspectives from physicians who have been involved in making these decisions, where discomfort and controversy are prominent despite sound ethical reasoning. There is also no mention of important aspects of withdrawal or withholding of IH and MPN, including the physical changes that occur to the child, how best to support other health care staff that are involved in the situation, and how to address staff who may not agree with the final decision.

The CPS Bioethics Committee published the most recent guideline in 2011: *“Withholding and withdrawing artificial nutrition and hydration”* (12). Written as a Practice Point, it captures the essential information conveyed by the AAP Guideline from Diekema and Botkin but incorporates the following additional points: 1) continuing appropriate medical care and palliative care measures for symptom management, 2) paying attention to, and supporting, the psychosocial needs of the family, 3) acknowledging that death may take weeks, and 4) acknowledging that support for members of the health care team including the option to opt out of caring for the child is imperative.

### **Pediatric Research on Withdrawing or Withholding IH and MPN**

So far, the main focus of this literature review has been on building the case for the ethical justification of withdrawing or withholding IH and MPN in certain circumstances. The evidence presented has primarily been expert opinion based on experience in bioethics and law. Unfortunately, very little research exists exploring pediatric physician attitudes about withdrawing or withholding IH and MPN and no surveys exist about withdrawal or withholding of IH and MPN explicitly.

Nelson et. al. reported unpublished survey data from a 1990 survey of the Pediatric Section of the Society of Critical Care Medicine (SCCM)(3). The scenario involved a four-month-old child who was comatose, unresponsive, and ventilator-dependent one month after an unexplained cardiorespiratory arrest. The parents insisted that all treatment stop and all physicians agreed that the child would make no neurologic recovery. In this scenario, 58% of respondents would not withdraw IH and MPN, compared to 14% who would not withdraw mechanical ventilation, and 2% who would not withhold CPR. When the scenario was changed to having the parents not insisting on stopping treatment, or willing to follow the recommendation of the physician, 65% of respondents would not withdraw IH and MPN. While the results highlight the perceived difference between IH and MPN compared to other forms of LST, conclusions are difficult to make given the lack of formal publication and peer review. The exact wording of the questions, response options, and response rate are also unknown.

Ashwal et. al. in 1992 conducted a similar survey of the Child Neurology Society looking at opinions of Pediatric Neurologists about pediatric PVS (69). The response rate was 26% (250 surveys) and examined issues around diagnosis, prognosis, and treatment of pediatric PVS. The survey asked about treatment preferences in pediatric PVS and included withdrawal or withholding of IH and MPN. Responses to foregoing IH were: 74% never recommend withholding IH, 20% sometimes, 6% always/frequently. Similar responses were seen with foregoing MPN: 75% never, 22% sometimes, 3% always/frequently. The publication described how these results were different from a similar adult survey of members of the American Neurological Association where 83% of respondents stated that it was ethical to remove IH and MPN. However, no further speculation was provided as to why the majority of respondents would not consider foregoing IH and MPN nor was there any discussion on why



pediatric PVS patients may be different in this regard compared to adult PVS patients.

Rubenstein et. al. conducted a survey of pediatric residents at their institution with the objective of exploring attitudes of their residents towards technologic support of vegetative patients. They hypothesized that attitudes would change over the course of training due to more exposure to seriously ill children, and that as residents gained experience, they would become more responsive to parental requests (68). Twenty-nine residents were surveyed yearly during their training, looking at their care preferences for a four-year-old male with PVS following a near-drowning episode at age 2 years, who develops respiratory failure following chronic aspiration. Residents were asked about withholding vasopressors, CPR, withdrawing IV fluids, nutrition, and respiratory support. Results showed that 41% of respondents would withdraw IV fluids, 35% would withdraw nutrition, but 100% would withhold vasopressors and CPR and 97% would withdraw respiratory support. Over time, more residents favoured withdrawal of IV fluids ( $p = 0.03$ ) and nutrition ( $p = 0.13$ ). Significantly fewer residents favoured withdrawal of IV fluids ( $p = 0.004$ ) and nutrition ( $p = 0.002$ ) if parents insisted on continuing all forms of treatment. An increased trend toward withdrawing IV fluids and nutrition was seen if parents requested discontinuation of all LST.

This survey, although small, was simple and clear. The results coincide with similar surveys of residents caring for adult patients. It was limited, however, by being a small part of a larger survey. The fact that residents are never the final decision maker also lends some artificiality to the question (68). Finally, there was no discussion as to the reasons for fewer residents wanting to withdraw IV fluids and nutrition than other forms of LST, which may have uncovered some of the notable misconceptions and controversies that exist around foregoing IH and MPN.

In 2005, Solomon et. al examined issues around foregoing IH and MPN in pediatric patients using a survey in an attempt to determine the extent to which pediatric physicians and nurses in ICU, hematology/oncology and other specialties were in agreement with one another and with published ethical recommendations regarding end-of-life care (1). The survey measured these responses using a pediatric version of the Decisions Near the End of Life Institutional Profile (99) which examined opinion items (respondents' agreement or disagreement with existing national guidelines), knowledge items (awareness of existing guidelines), and belief items (respondents' attitudes and concerns about the care they provide) using a 5-point Likert scale. This profile had been developed for adult practitioners with strong validity and excellent test-retest repeatability (99). The pediatric version of the instrument was validated by national pediatric experts in end-of-life care and scored similar consistency scores on test-retest repeatability compared to the original instrument (1).

Questions were constructed as false statements. There was one question on foregoing IH and MPN that was used to examine knowledge of existing guidelines, which state that foregoing IH and MPN is ethically permissible. It read as follows:

“Even if life supports such as mechanical ventilation and dialysis are stopped, medically supplied food and water should always be continued. (1)”

Results showed no difference between pediatric specialties (209 physicians responded) but did show incongruence with published guidelines (Table 1).

**Table 1.** Response of pediatric physicians to false statement regarding foregoing IH and MPN (adapted from Solomon et. al. (1)).

	<b>Agree (%)</b>	<b>Uncertain (%)</b>	<b>Disagree (%)</b>
<b>PCCM (n = 25)</b>	36	12	52
<b>Hematology/Oncology (n = 53)</b>	25	26	49
<b>Other (n = 151)</b>	45	17	37
<b>Residents (n = 116)</b>	42	21	37

The authors discussed some limitations in the wording of the question as there may have been variable interpretation of “medically supplied food and water” to mean by mouth or IV or either method (1). However, even if confusion existed, there was considerable variation, which the authors interpreted as having significant implications. Given the ethical permissiveness of withdrawing or withholding IH and MPN, these implications included the potential for conflict among HCPs, confusing messages to parents, and possible inappropriate prolongation of dying (1). The authors did not go into further depth in discussion on the responses to this question, nor did they offer alternative explanations for digression of opinion from published guidelines. Overall, the study was well-done using a validated questionnaire, but only explored one small aspect of withdrawal and withholding of IH and MPN.

The final study was published in 2012 by Feltman et. al. who surveyed neonatologists through the AAP Perinatal section, exploring attitudes toward limiting LST in the NICU (100). The survey used 4 hypothetical scenarios to explore major ethical concepts around withdrawal of LST. Two concepts explored were withdrawal of PN and IV fluids, and withdrawal of EN. In all scenarios, less than 10% of neonatologists refused the options of non-escalation of care, do-not-resuscitate and

withdrawal of mechanical ventilation but over 30% of neonatologists refused to withdraw PN, IH or EN. Of the respondents who agreed to withdraw, the most frequent choice was if the decision was in agreement to a family's request rather than themselves offering or strongly recommending the option. Respondents felt the most discomfort with withdrawal of IH and MPN (20%) compared to other LST. This study allowed for free-text entry by respondents to further explain their choices. Common reasons for not offering withdrawal of IH and MPN, and/or having personal discomfort in offering its withdrawal were: concerns over patient discomfort/suffering, considering IH and MPN as 'basic' rather than 'extraordinary' or 'heroic' care, and causing more emotional difficulty for parents or other healthcare staff. (100)

This study was limited by a response rate of 17% but did find similar results to prior publications that used surveys constructed around hypothetical case scenarios. Their exploration of the reasons why withdrawing IH and MPN is different from withdrawal of other LST showed that misconceptions about IH and MPN causing excess suffering and being routine care still exist. This exploration also showed that the majority of respondents did grant wide parental discretion in the decisions involving withdrawal or withholding of IH and MPN, in keeping with published recommendations (6,12). While the free-text options of the survey provided some compelling information, the number of respondents who chose to offer their reasons was not reported. The authors also acknowledged that decision-making may be different when practitioners are faced with actual clinical situations, similar to prior studies where only theoretical clinical scenarios were examined.

## **Conclusions**

The decision to withdraw or withhold IH and MPN is complex and filled with many ethical challenges. In the context of a child's life, these challenges are magnified because of the relative rarity of the situation arising and the strong emotional connotations surrounding the feeding and death of a child. A sound ethical framework exists which makes foregoing IH and MPN in children ethically permissible but never ethically required. This framework has been used to construct clinical guidelines for pediatricians to help guide their decision-making when confronted with these situations. However, these guidelines, while providing a sound theoretical framework, do not reflect the difficulty in foregoing IH and MPN in actual situations. In addition, they have been constructed with little pediatric research into this area and have relied on extrapolation from similar adult studies and from legal decisions in pediatric PVS cases.

## **Research Question**

Based on the above argument, my research question is: "What factors do Canadian pediatric physicians and residents consider when deciding to withdraw or withhold intravenous hydration or medically provided nutrition in infants and children with a serious or terminal medical condition?"

## **Objectives**

The primary objective of this study is to explore attitudes and opinions of Canadian pediatric physicians and residents that influence their decision to withdraw or withhold intravenous hydration or medically provided nutrition.

Secondary objectives include:

- To identify clinical parameters which influence these decisions.
- To determine if the approaches of Canadian pediatric physicians are consistent with published guidelines.
- To examine whether increasing experience with making these decisions changes attitudes and values.
- To explore which clinical parameters are used in decision-making.
- To identify if what “ought to be done/recommended” is actually occurring in real-life situations?

## **Hypotheses**

1. These situations occur rarely even in pediatric specialties so the response rate may be low.
2. The majority of respondents will be practitioners with experience because of the memorable nature of these situations.
3. A wide range of opinion is expected; however specific practitioner and clinical parameters are expected to emerge as important aspects of the final decision.
4. Practitioners with life or clinical experience will identify specific aspects of foregoing IH and MPN that make these decisions difficult or uncomfortable.

The goal of my research is to add to the existing knowledge by identifying which patient and practitioner factors influence the final decision to forego IH and MPN. Identification of these attitudes and opinions needs to occur because the complexity of these situations can lead to a wide range of approaches, some of which may be less appropriate than others. The results may help clinicians to gain a better understanding of the level of variability, which may lead to future improvement in existing guidelines.

### III

## Methods

### Survey

The research question was addressed by using an electronically distributed survey. Survey participants were given six hypothetical case scenarios. These represented hypothetical but relevant situations where withdrawal or withholding of all or some aspects of IH and MPN could be considered. The survey also collected demographic information and asked members about their own experience withdrawing or withholding IH and MPN. Opinions on the perception of IH and MPN as medical therapies, their ethical perceptions of IH and MPN and the influence of personal and professional attributes on their decision-making were also solicited from the respondents. The full text of the survey questions and case scenarios can be found in Appendix II.

### Design

The survey was constructed from an original concept (Appendix I) through multiple steps. Questions based on the study objectives were created through discussion between the author and local experts with significant experience in Pediatric Palliative Care, Neonatal Intensive Care, and bioethics (Dr. D. Davies, Dr. P. Byrne). Content for the questions was derived from issues and knowledge gaps revealed through the extensive literature review. Additional concepts on general survey design were acquired through my own experience, course-work, literature review, and

consultation with local individuals with survey expertise (Dr. P. Byrne, C.Alloway).

### **Validation**

After revision of the original survey, content validity was assessed in two separate steps. On two separate occasions, the survey was circulated to ten individuals representing multiple specialties in Pediatric Medicine (General Pediatrics, Neurology, Hematology/Oncology/Palliative Care, Pediatric Critical Care Medicine, Neonatal Intensive Care, Pediatric Residents). The survey was further modified after completion of these pilot surveys based on feedback and suggestions from participants.

The second step for ensuring content validity was through exhaustive review of the survey by the Bioethics Committee of the Canadian Paediatric Society (CPS). The Canadian Paediatric Society is the major professional association for pediatricians in Canada. The CPS represents over 3000 pediatricians and other health care providers who care for children (101). The CPS Bioethics Committee is comprised of Canadian Pediatric Physicians with expertise in the field of bioethics, and its mandate is to provide expert advice, develop guidelines and recommendations, and advocate on behalf of Canadian children on issues of a bioethical nature (102). Committee members reviewed the survey and provided recommendations to ensure the survey would answer its stated objectives in a concrete, clear, and concise manner. The committee reviewed the revised surveys on multiple occasions until saturation was achieved.

The final survey consisted of three major sections:

1. Six case studies in which withdrawal or withholding of IH and MPN could be considered. Survey respondents were asked to provide their opinion on whether withholding or withdrawing of IH,



parenteral nutrition (PN) or enteral nutrition (EN) were reasonable options given the clinical situation.

2. Demographic questions included years of experience, practice type, age, and gender.
3. Specific questions explored common views, values, guidelines, and conflict management related to withdrawal or withholding of IH and MPN.

The responses to the patient cases and the opinion-specific questions were constructed using a five-point Likert scale. A Likert scale response option increases the variance of responses, and hence increases the accuracy compared to a dichotomous response option. The choice of a five-point Likert scale was arbitrary and was based on striking a balance between item variance and ease of administration (103).

### **Distribution**

The survey was distributed via electronic mail which provided a direct URL link to the survey on the host website (SurveyMonkey<sup>®</sup>, Palo Alto, California, [www.surveymonkey.net](http://www.surveymonkey.net)). Permission was granted by the CPS in May 2011 to distribute the survey to its general membership. As the CPS membership is voluntary, to ensure pediatric specialists in disciplines of interest to our survey (H/O/P, PCCM) were not missed, the survey was also distributed electronically to all PCCM physicians in Canada through their available electronic mail addresses; and to the general physician membership of the C<sup>17</sup> Children's Cancer and Blood Disorders Network. The C<sup>17</sup> is an organization representing the interests of children and adolescents with cancer and blood disorders and acts as an authoritative voice for these patients through research, education and advocacy (104). Membership is composed of Pediatric Hematology/Oncology physicians from the 17 hematology, oncology and stem cell transplant programs across Canada (104). The survey was distributed a second time to the

same organizations to ensure capture of respondents who may have not participated after the first distribution.

### **Sample Size Calculation**

To determine an appropriate sample size, an effect size of 0.15 was used as this was felt to be a clinically relevant difference between each choice (strongly agree, agree, neutral, disagree, strongly disagree) on a five-point Likert scale. Effect size is a standardized mean difference between two groups. Sample sizes were calculated for both linear and logistic regression models as it was not known prior to reviewing survey results which models would best fit the outcomes.

Using multiple linear regression and 8 predictors, 108 surveys would be required assuming 80% power desired to detect an effect size of 0.15 using a significance level of 0.05.

Adjusting the model for non-linear outcome, multiple logistic regression would have to be used with a collapsed binary version of the outcome (i.e. Yes/No; Agree/Disagree). Ninety-four surveys would be needed for 1 predictor only, assuming 80% power, 0.05 significance level and that the baseline probability of responding 'Yes/Agree' is 40% (i.e. when continuous predictors are at their mean values) to detect an Odds Ratio of 1.8. Under the same assumptions (80% power, 0.05 alpha level, baseline probability of 40%), but with the further assumptions that other predictors in the model explain 10% of the variability in the response, 105 surveys would be needed.

A review of each major pediatric centre for the number of pediatricians and residents, and pediatric specialists and fellows in Oncology, Palliative Care, PICU, NICU and Neurology yielded approximately 800 possible participants. This was felt to be an ample pool of survey responders to

achieve adequate power even with a response rate under 15%. A lower response rate brings other issues such as lack of representative opinion into the analysis but power should not be compromised.

### **Statistical Analysis**

Data were analyzed using IBM® SPSS® Statistics Version 19 (IBM Corporation, Somers, NY). Univariate and summary statistics were obtained for all variables and distributions evaluated. Reliability testing was performed from arbitrarily selected questions from the survey and is reported using Cronbach's  $\alpha$  statistic. To explore the effect of experience on opinions, values and conflict, I used Chi-square analysis to compare responses from survey participants with prior experience of foregoing IH and MPN in their patients to those without experience. Analysis of factors which contributed to the opinion of the survey participants was done using established methods for measuring correlation (Pearson correlation, Kendall's Tau statistic) and logistic regression where appropriate. Depending on the distribution of responses of the Likert-based questions, for multiple logistic regression analysis, the extreme values (strongly agree, strongly disagree) were combined with their corresponding less extreme values (agree, disagree) for more interpretable analysis.

## IV

### Results

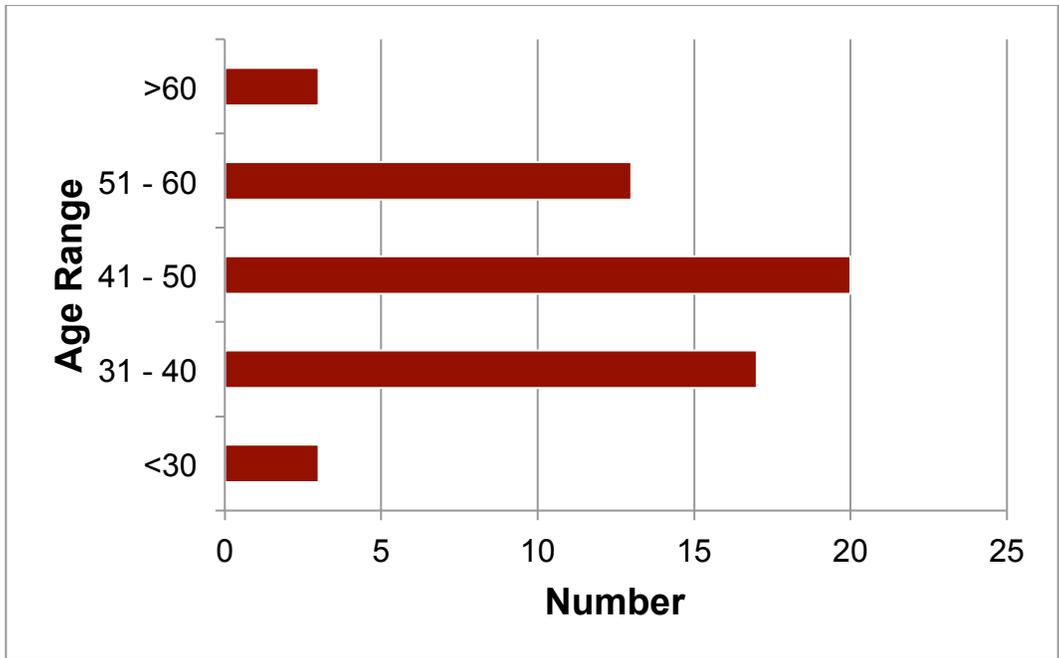
#### Response Rate

Sixty surveys were completed. Four surveys had only the case scenarios completed. Their answers were included in the analysis of the case scenarios but were excluded from further analysis. While response rate for the overall population was low (60/800, 7.5%) stratification by pediatric specialty showed higher response rates in Hematology/Oncology/Palliative Care (25/105, 24%) and Pediatric Critical Care Medicine (15/84, 18%).

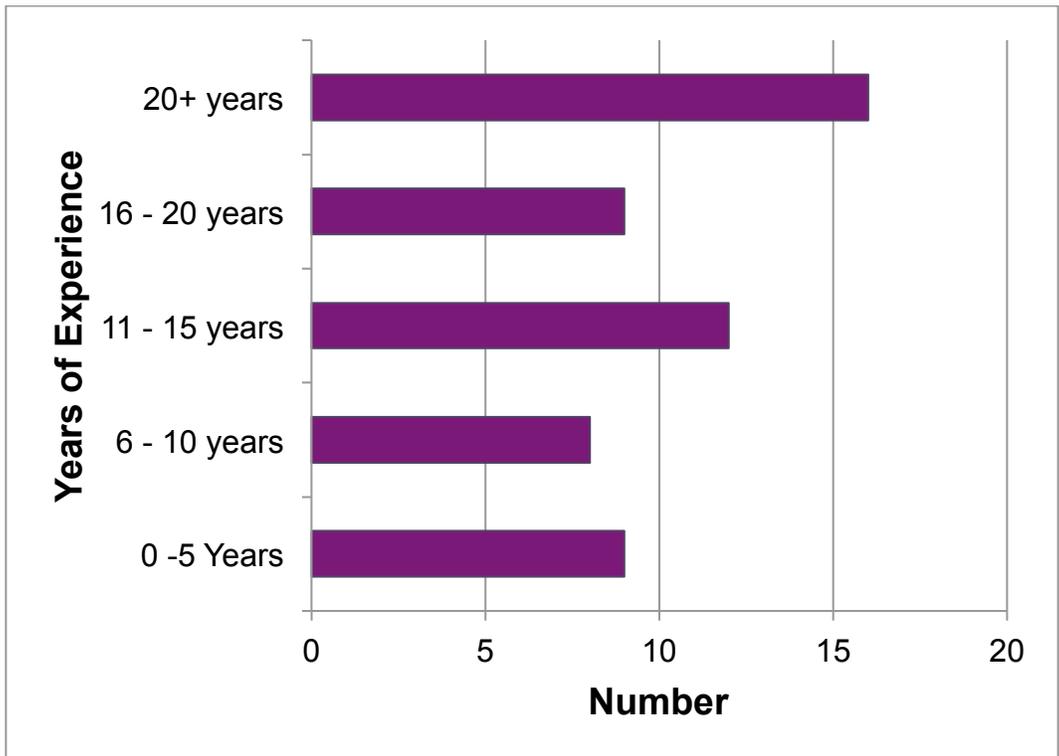
#### Demographics

Demographic data are presented descriptively. Thirty-two (57%) female physicians and 24 (43%) male physicians participated in the survey. Most respondents were between the ages of 41 and 50 years of age (20, 36%, Figure 1) and had 20 years or more practice experience (16, 29%, Figure 2). Four residents completed the survey (General Pediatrics, 2, PCCM, 2).

Four main pediatric specialties represented 97% of respondents with 2 specialties most likely to encounter situations of withdrawing or withholding IH or MPN comprising the majority (H/O/P, 45.0%, PCCM, 23.0%; Table 2). Fifty-two respondents (94%) worked in an academic-based hospital.



**Figure 1.** Age distribution of survey respondents.



**Figure 2.** Level of Pediatric experience reported.

**Table 2.** Representation of pediatric specialties among survey respondents.

<b>Specialty</b>	<b>Frequency (Percent)</b>
Hematology/Oncology/Palliative Care	25 (45.0)
Pediatric Critical Care Medicine	13 (23.0)
General Pediatrics	9 (16.0)
Neonatal Intensive Care	5 (9.0)
Other*	2 (3.5)
Did not answer	2 (3.5)

\*Neurology (1), Metabolic (1)

### **Reliability Testing**

Sampling of a variety of survey questions revealed strong reliability on Cronbach's  $\alpha$  testing. Questions sampled included all six case scenarios (Cronbach's  $\alpha$  range of 0.602 (Case 6) to 0.951 (Case 2)), and 3 opinion questions: question 10-3 (How do you think the following attributes have contributed to shaping your clinical decisions on these issues?

Cronbach's  $\alpha = 0.735$ ), question 14-1 (What, if any, situations might you or have you considered forgoing artificially provided hydration/nutrition?

Cronbach's  $\alpha = 0.818$ ), and question 20-1 (Do any of these factors influence your view on withholding/withdrawing artificially provided hydration/nutrition? Cronbach's  $\alpha = 0.735$ ).

### **Case Scenarios**

Responses and overall pattern of responses to the case scenarios are summarized for each case in Tables 3 – 8. General overall trends which were reflected in the cases included fewer recommendations to withdrawal or withhold IH and MPN in instances where there was more uncertainty about prognosis, more parental uncertainty about goals of care for the

child, or evidence that IH and/or MPN was not having a negative impact on the patient's status.

**Table 3. Case 1:** 14-year-old patient with neurologic devastation and who meets criteria for persistent vegetative state (PVS). Parents initiate discussion about withdrawal of IH and MPN (n = 60).

	<b>Recommend continuing/ initiating</b>	<b>Neutral</b>	<b>Recommend withholding/ withdrawing</b>	<b>Insufficient information to form a recommendation</b>
<b>Parenteral Nutrition</b>	1	3	<b>54*</b>	2
<b>Enteral Feeding</b>	5	8	<b>44*</b>	3
<b>Intravenous Hydration</b>	9	8	<b>39*</b>	3
<b>Response summary:</b> Fairly strong recommendation to withdraw, which is consistent with published literature on withdrawal of MPN in children with PVS.				

*\*Responses with the highest frequency are in bold for Tables 2-7*

**Table 4. Case 2:** Patient from case 1 does not meet PVS criteria, parents still ask about withdrawal of IH and MPN (n = 59).

	<b>Recommend continuing/ initiating</b>	<b>Neutral</b>	<b>Recommend withholding/ withdrawing</b>	<b>Insufficient information to form a recommendation</b>
<b>Parenteral Nutrition</b>	17	11	<b>23</b>	8
<b>Enteral Feeding</b>	<b>27</b>	9	14	9
<b>Intravenous Hydration</b>	<b>26</b>	12	14	7
<b>Response summary:</b> See more of a shift away from withdrawal/withholding and a more cautious "wait and see" approach.				

**Table 5. Case 3:** Neonatal patient with severe hypoxic-ischemic brain injury. Parents did not initiate discussion about withdrawal of IH and MPN (n = 58).

	<b>Recommend continuing/ initiating</b>	<b>Neutral</b>	<b>Recommend withholding/ withdrawing</b>	<b>Insufficient information to form a recommendation</b>
<b>Parenteral Nutrition</b>	19	14	<b>20</b>	5
<b>Enteral Feeding</b>	<b>33</b>	16	5	4
<b>Intravenous Hydration</b>	<b>29</b>	18	8	4
<b>Response Summary:</b> See a shift away from withdrawal/withholding EN and IH. May be a reflection of less certainty of prognosis in neonatal patients?				

**Table 6. Case 4:** Total intestinal failure in a neonatal patient. Parents have no clear opinion on feeding wishes (n = 59).

	<b>Recommend continuing/ initiating</b>	<b>Neutral</b>	<b>Recommend withholding/ withdrawing</b>	<b>Insufficient information to form a recommendation</b>
<b>Parenteral Nutrition</b>	<b>35</b>	9	11	4
<b>Enteral Feeding</b>	<b>26</b>	13	14	5
<b>Intravenous Hydration</b>	<b>37</b>	14	7	1
<b>Response summary:</b> Strong recommendation to continue which may reflect advances in feeding support and improvements in bowel transplantation that are not yet reflected in published literature.				



**Table 7. Case 5:** 6-year-old patient with advanced, untreatable malignancy who is having difficulty with enteral feeding secondary to vomiting and lethargy. The parents are not at same level of comprehension as the medical team regarding goals of care (n = 59).

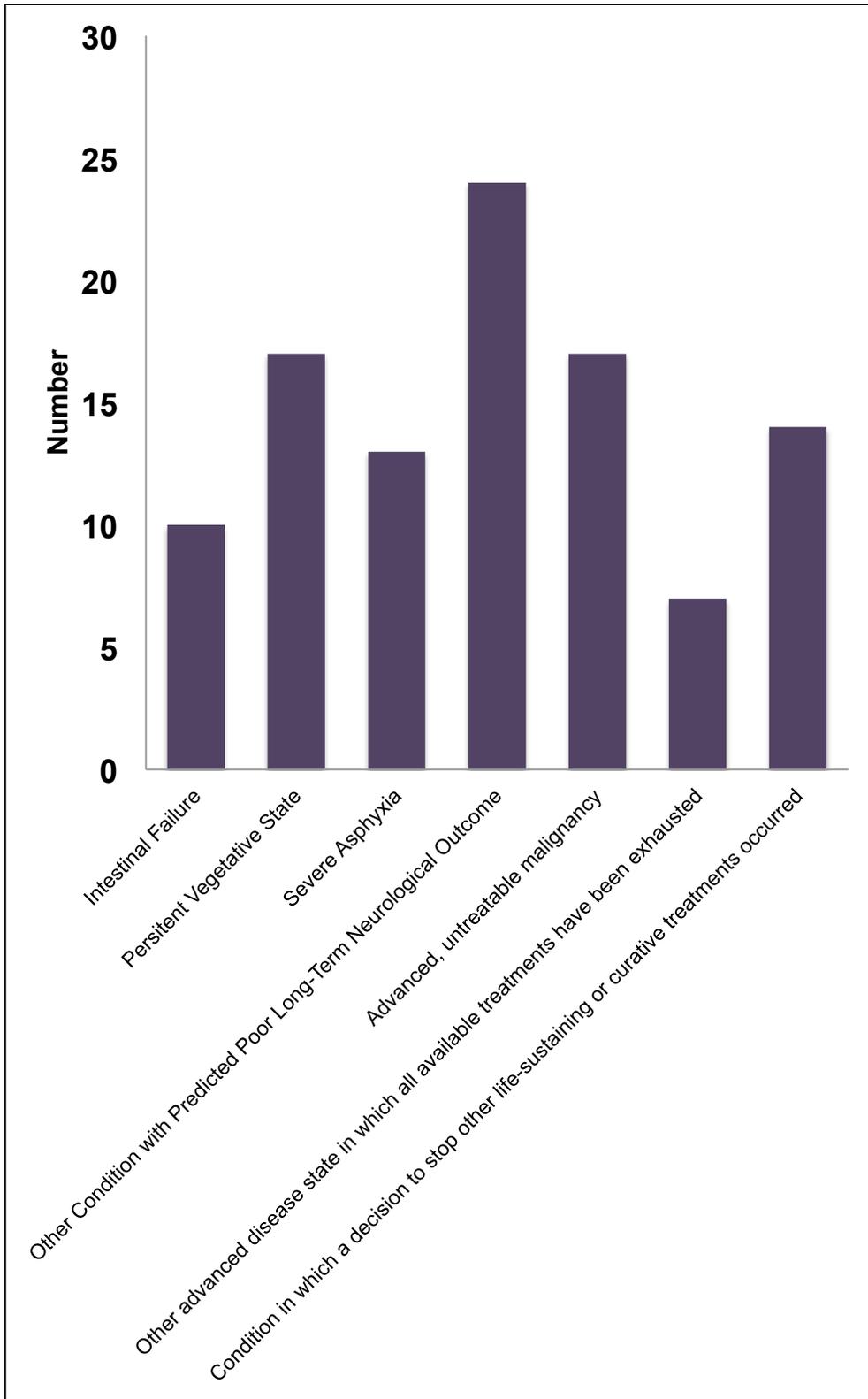
	<b>Recommend continuing/initiating</b>	<b>Neutral</b>	<b>Recommend withholding/withdrawing</b>	<b>Insufficient information to form a recommendation</b>
<b>Parenteral Nutrition</b>	11	9	<b>37</b>	2
<b>Enteral Feeding</b>	17	12	<b>23</b>	6
<b>Intravenous Hydration</b>	<b>26</b>	17	13	3

**Response summary:** TPN seen as not beneficial and maybe futile given patient's prognosis. Similar trend with enteral feeding due to patient's negative symptoms but there appears to be more of a drift to continuing EN. Respondents did not feel need to withdraw/withhold IH at this point.

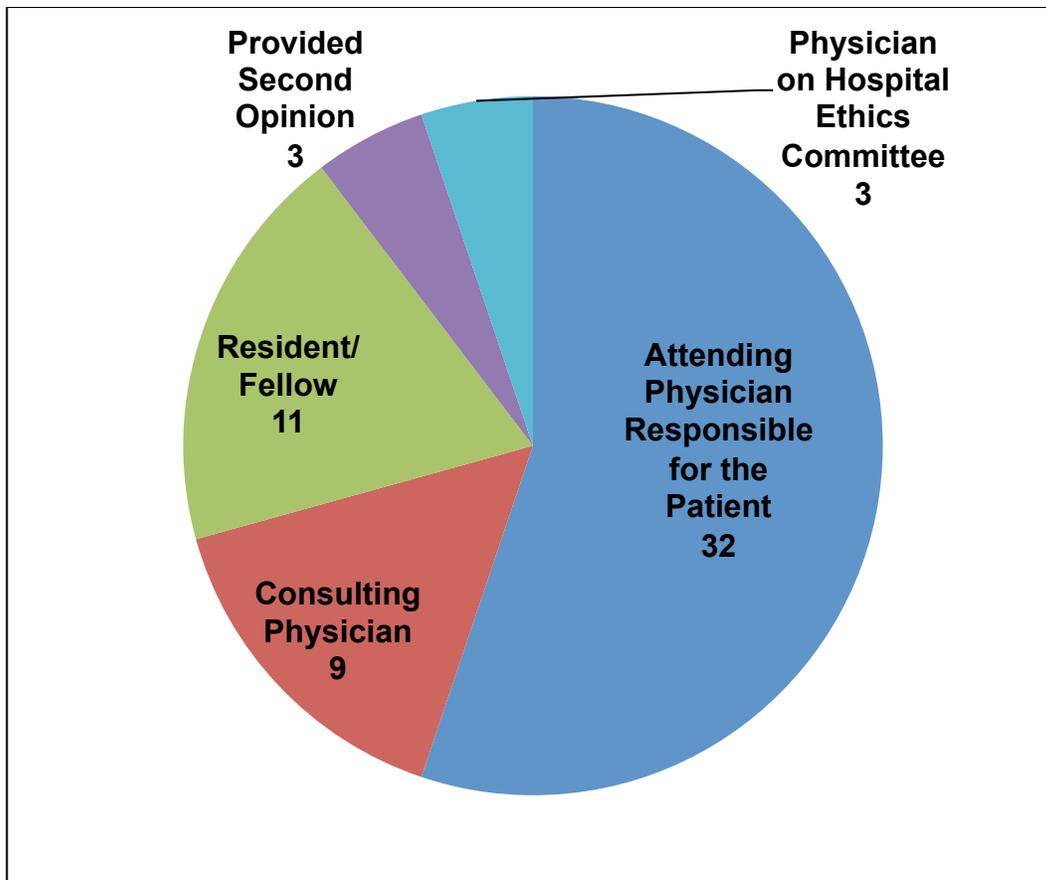
**Table 8. Case 6:** 5-year-old patient with advanced, untreatable malignancy; some intolerance of nasogastric feeding. Parents have accepted end-stage nature of disease but want to continue current supportive nutrition measures as he is interactive during the day (n = 57).

	<b>Recommend continuing/initiating</b>	<b>Neutral</b>	<b>Recommend withholding/withdrawing</b>	<b>Insufficient information to form a recommendation</b>
<b>Parenteral Nutrition</b>	24	8	<b>25</b>	0
<b>Enteral Feeding</b>	<b>25</b>	6	<b>25</b>	0
<b>Intravenous Hydration</b>	<b>41</b>	6	10	0

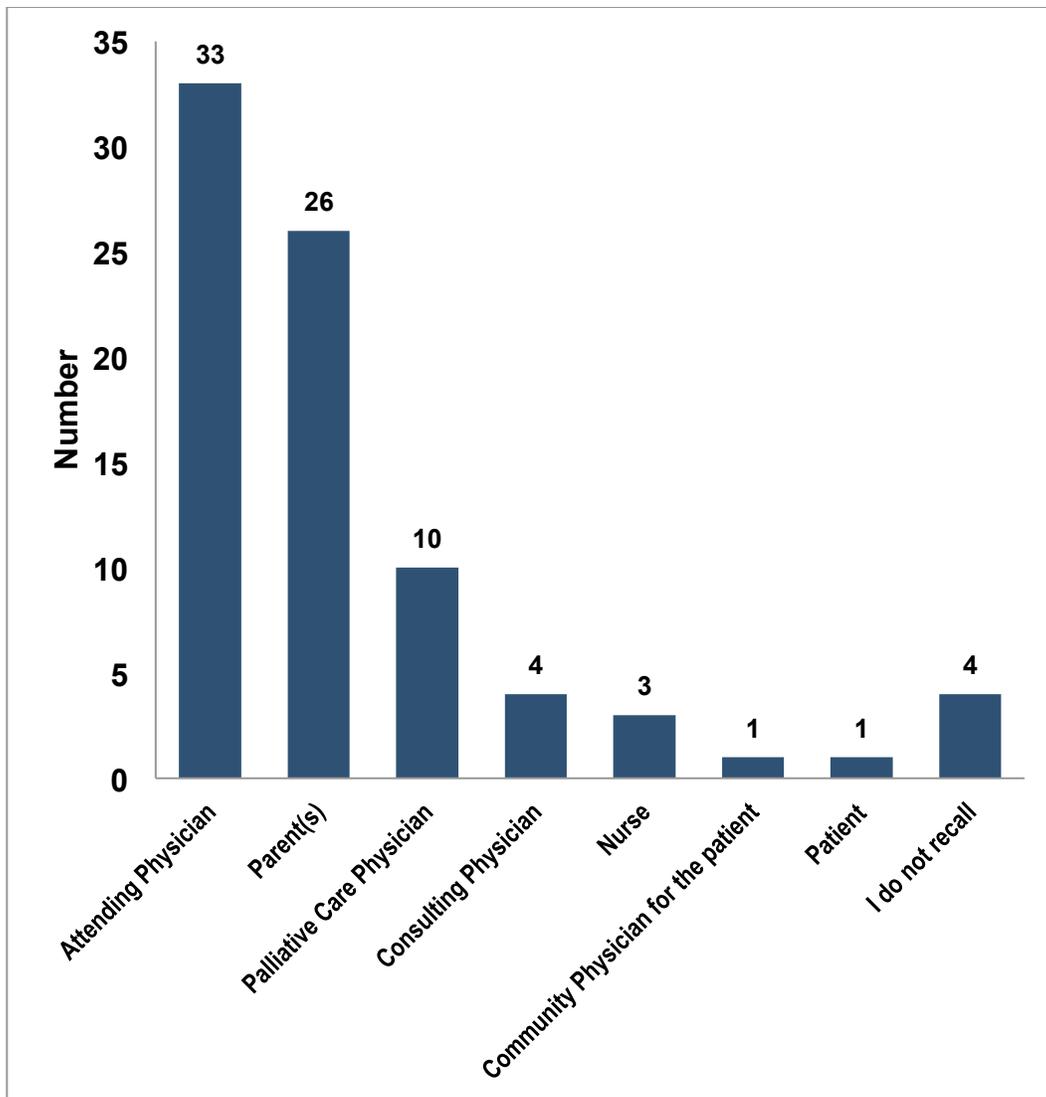
**Response summary:** Split in responses for PN and EN, possibly due to different weighting of risks and benefits by individual respondents. Respondents did not feel the need to withdraw/withhold IH at this point, possibly due to level of alertness and interactivity of patient at this point.



**Figure 3.** Circumstances in which physicians have withdrawn or withheld IH and MPN (n = 102). Respondents were permitted to choose more than one option.



**Figure 4.** Roles of respondents who have withdrawn or withheld IH and MPN (n = 58). Respondents were permitted to choose more than one option.



**Figure 5.** Responses to the Question: Who initiated the discussion about withdrawal or withholding IH and MPN (n = 82)? Respondents were permitted to choose more than one option.

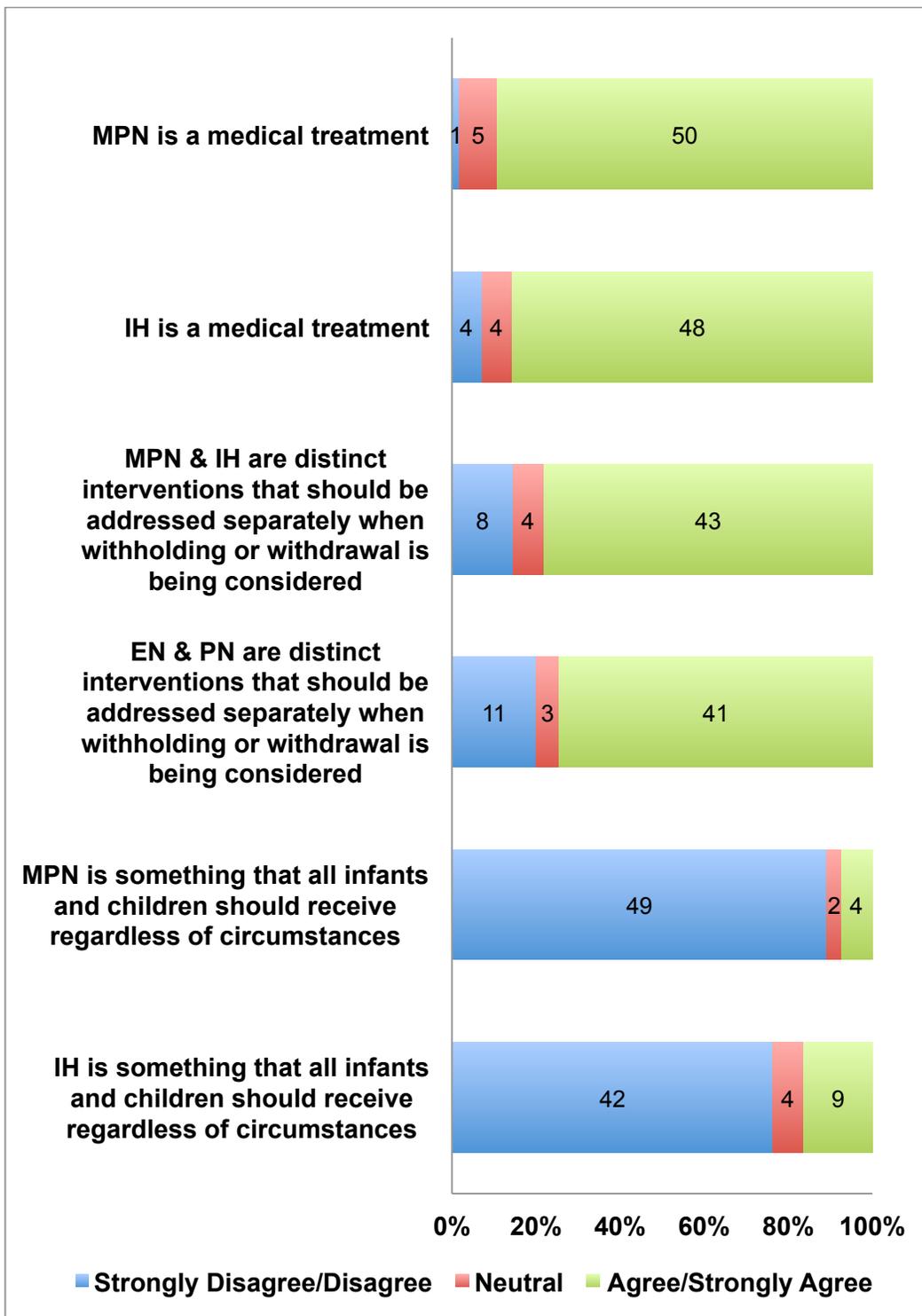
## **Experience**

Forty-nine respondents (88%) had previous experience of withdrawing or withholding IH and MPN across a variety of circumstances (Figure 3). Most respondents (65%) were the attending physicians responsible for the patient but other roles were also represented (Figure 4). The attending physician initiated the discussion in the majority of circumstances, followed closely in frequency by parental initiation (Figure 5). A physician involved in the care of the patients initiated the discussion 59% of the time.

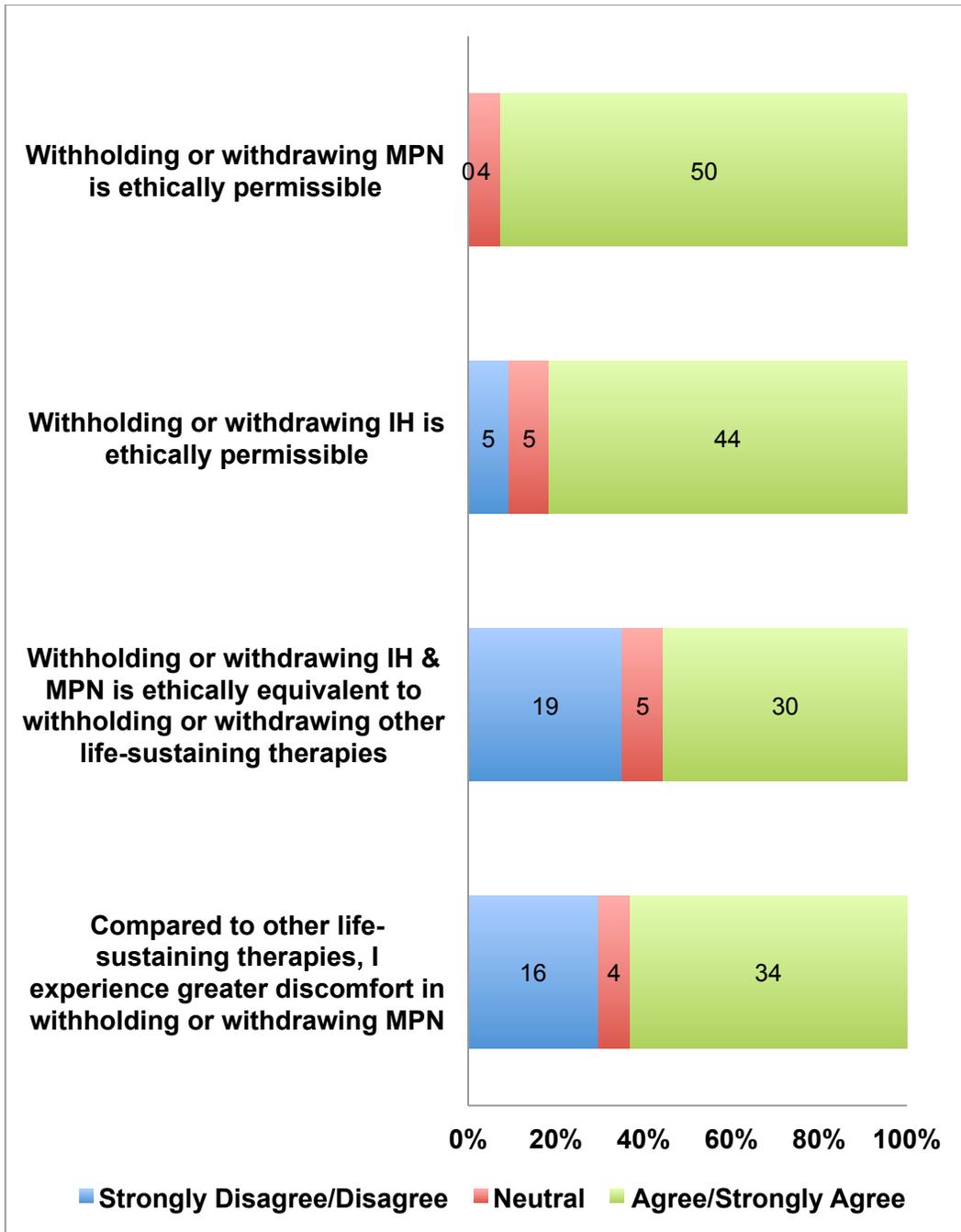
## **Opinion**

Almost all respondents felt that IH and MPN were medical treatments (86% and 89% respectively; Figure 6), and that they should be addressed separately during discussions about withdrawal of other life-sustaining therapies (IH and MPN: 78%, EN and PN: 75%; Figure 5). Most respondents disagreed that IH and MPN should be given to all children regardless of circumstances (76% and 89% respectively; Figure 6).

While almost all respondents agreed that withdrawal or withholding of IH and MPN were ethically permissible (81% and 93% respectively; Figure 7), fewer respondents felt IH and MPN were ethically equivalent to other life-sustaining therapies (56%). Compared to other life-sustaining therapies most respondents felt greater discomfort with withdrawal or withholding of IH and MPN (63%, Figure 7).



**Figure 6.** Opinion of respondents regarding the role of IH and MPN in the care of the child.



**Figure 7.** Opinion of respondents about the ethical context of IH and MPN.

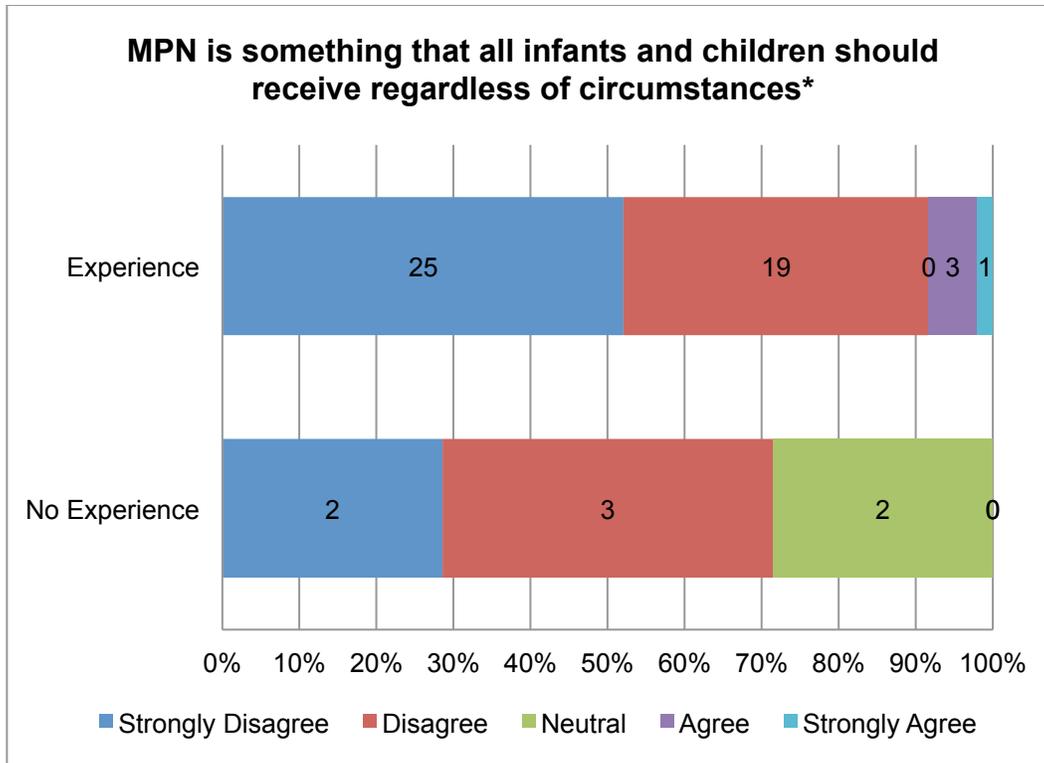
Respondents who reported experience (n = 49) with withholding or withdrawing IH and MPN were compared to respondents who did not have experience (n = 7) to examine if previous experience altered their opinion. Statistically significant differences were found in 2 instances:

1. Compared to respondents with no experience, a larger proportion of respondents with experience (4 respondents (8%) vs. 0 non-experienced respondents) disagreed or strongly disagreed that MPN is something that all infants and children should receive regardless of circumstances (Table 9, Figure 8, p = 0.005). Also seen was 4 respondents (8%) with experience who agreed or strongly agreed with this statement compared to zero non-experienced respondents who chose these responses.
2. Compared to respondents with no experience, a larger proportion of respondents with experience agreed or strongly agreed that withholding or withdrawing IH is ethically permissible (Table 9, Figure 9, p = 0.018). A similar trend was seen with MPN (Table 9, p = 0.061).

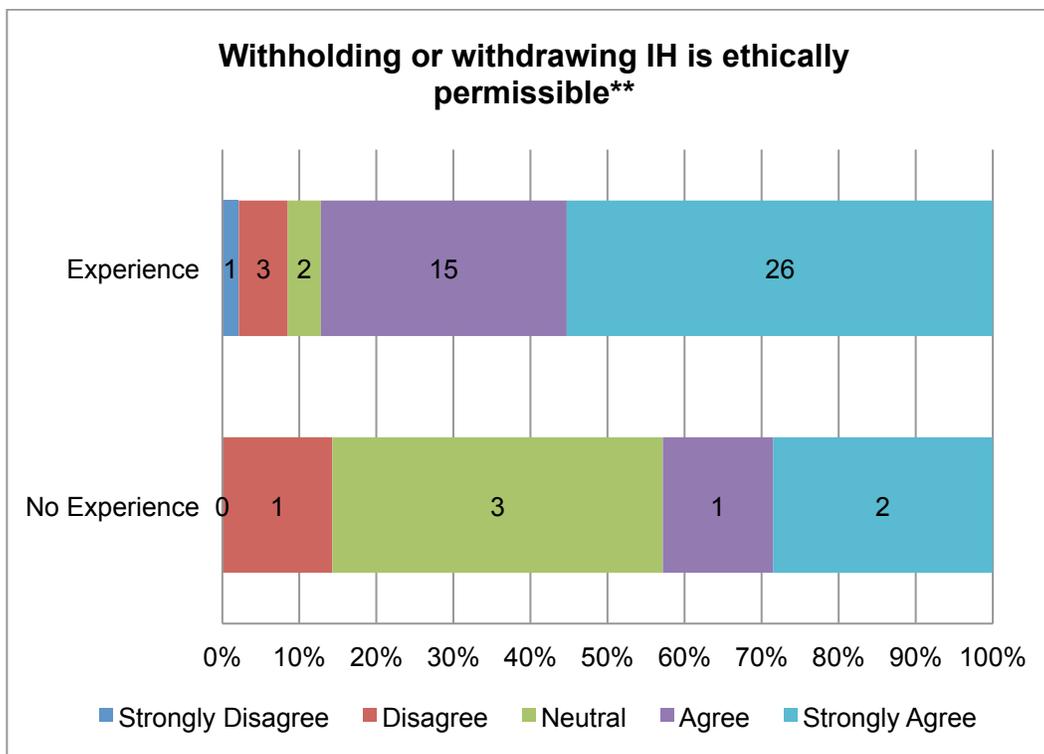


**Table 9.** Opinions compared between respondents with and without experience.

Prior Experience	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	p value
<b>MPN is a medical treatment (n = 56).</b>						
Experience	0	1	4	22	22	.938
No Experience	0	0	1	3	3	
<b>IH is a medical treatment (n = 56).</b>						
Experience	1	2	4	19	23	.698
No Experience	0	1	0	2	4	
<b>MPN &amp; IH are distinct interventions that should be addressed separately when withholding or withdrawal is being considered (n = 55).</b>						
Experience	2	6	3	28	9	.745
No Experience	0	0	1	5	1	
<b>EN &amp; PN are distinct interventions that should be addressed separately when withholding or withdrawal is being considered (n = 55).</b>						
Experience	1	9	2	25	11	.819
No Experience	0	1	1	3	2	
<b>MPN is something that all infants and children should receive regardless of circumstances (n = 55).</b>						
Experience	25	19	0	3	1	.005
No Experience	2	3	2	0	0	
<b>IH is something that all infants and children should receive regardless of circumstances (n = 55).</b>						
Experience	19	19	3	5	2	.591
No Experience	2	2	1	2	0	
<b>Withholding or withdrawing MPN is ethically permissible (n = 54)</b>						
Experience	0	0	2	20	25	.061
No Experience	0	0	2	3	2	
<b>Withholding or withdrawing IH is ethically permissible (n = 54)</b>						
Experience	1	3	2	15	26	.018
No Experience	0	1	3	1	2	
<b>Withholding or withdrawing IH &amp; MPN is ethically equivalent to withholding or withdrawing other life-sustaining therapies (n = 54)</b>						
Experience	3	13	4	16	11	.572
No Experience	0	3	1	3	0	
<b>Compared to other life-sustaining therapies, I experience greater discomfort in withholding or withdrawing MPN (n = 54)</b>						
Experience	4	11	3	24	5	.569
No Experience	0	1	1	3	2	



**Figure 8.** Comparison of opinion on receipt of MPN between respondents with and without experience.\*p = 0.005



**Figure 9.** Comparison of opinion on ethics of withholding or withdrawing IH between respondents with and without experience.\*\*p = 0.018

## Values

Questions 10-2, 10-3 (Table 10) and 20-1 (Table 11) addressed personal and professional attributes that could contribute to respondents' views and clinical decisions on withdrawing or withholding IH and MPN.

Thirty-five respondents (63.6%) indicated that their personal beliefs did not significantly influence their professional recommendations on issues of withdrawing or withholding IH and MPN (Question 10-2).

Question 10-3 asked whether religion, culture, family, and personal attributes contributed to shaping clinical decisions. The majority of respondents (50.9%) stated that religion had no contribution with 30.9% indicating that religion definitely had no contribution. Question 20-1 also asked if religious beliefs influence respondents' views on withdrawing or withholding IH and MPN. Again the majority (54.5%) strongly disagreed or disagreed. The Pearson correlation between both stems was strong and significant (Pearson coefficient 0.611,  $p < 0.0001$ ).

Cultural and familial attributes showed more varied contributions with both clustering around neutral (Table 10). The majority of respondents (76.4%) stated that personal attributes contributed (50.9%) or strongly contributed (25.5%) to shaping their clinical decisions. Correlation with factors in question 20-1 showed significant, but weak correlation with previous positive personal experience (Pearson coefficient 0.445,  $p = 0.001$ ) and previous negative personal experience (Pearson coefficient 0.413,  $p = 0.002$ ). No significant correlation was seen between personal attributes and religious beliefs, own emotional comfort, and ethical concerns.

**Table 10.** Responses to the Question: How do you think the following attributes have contributed to shaping your clinical decisions on these issues? (n = 55) *Most frequent responses are highlighted in bold text.*

	<b>Strong Contribution (%)</b>	<b>Moderate (%)</b>	<b>Neutral (%)</b>	<b>None (%)</b>	<b>Definitely No Contribution (%)</b>
<b>Religion</b>	5 (9.1)	9 (16.4)	13 (23.6)	11 (20.0)	<b>17 (30.9)</b>
<b>Cultural</b>	1 (1.8)	<b>25 (45.5)</b>	14 (25.5)	9 (16.4)	6 (10.9)
<b>Familial</b>	1 (1.8)	12 (21.8)	<b>18 (32.7)</b>	15 (27.3)	9 (16.4)
<b>Personal</b>	14 (25.5)	<b>28 (50.9)</b>	7 (12.7)	2 (3.6)	4 (7.3)
<b>Other</b>	<b>7 (26.9)</b>	5 (19.2)	6 (23.1)	2 (7.7)	6 (23.1)
<i>Parent opinion</i>	2	1			
<i>Experience</i>	5	1			
<i>Not Specified</i>		3	6	2	6

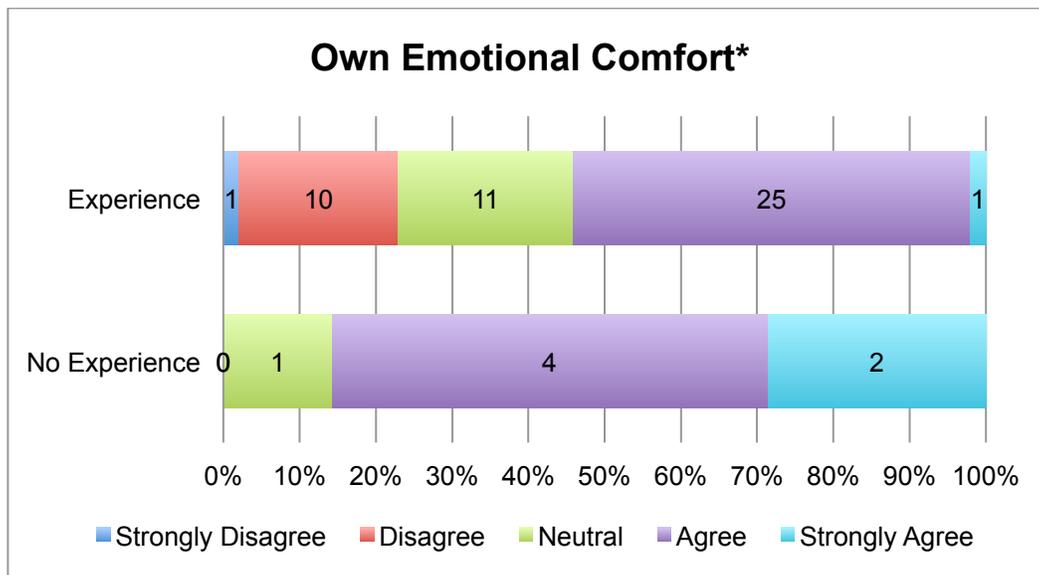
Respondents identified several factors that they felt influenced their views on withholding or withdrawing MPN and/or IH: previous professional experiences (both positive and negative), type of medical practice, ethical concerns and their own emotional comfort. The majority of respondents felt that medico-legal concerns and their own religious beliefs did not influence their views. Neutral factors included previous personal experiences (both positive and negative) and institutional policy.

Logistic regression was used to examine if any factors in questions 10-3 and 20-1 influenced the choice in question 10-2 (63.6% of respondents indicated that their personal beliefs did not influence their professional recommendations). No significant factors were identified in the regression model.

**Table 11.** Responses to the Question: Do any of these factors influence your view on withholding/withdrawing artificially provided hydration/nutrition? (n = 55) *Most frequent responses are highlighted in bold text.*

	<b>Strongly Disagree (%)</b>	<b>Disagree (%)</b>	<b>Neutral (%)</b>	<b>Agree (%)</b>	<b>Strongly Agree (%)</b>
<b>Previous positive professional experience</b>	1 (1.8)	6 (10.9)	9 (16.4)	<b>34 (61.8)</b>	5 (9.1)
<b>Previous negative professional experience</b>	3 (5.5)	16 (29.1)	12 (21.8)	<b>22 (40.0)</b>	2 (3.6)
<b>Previous positive personal experience</b>	6 (11.5)	13 (25.0)	<b>19 (36.5)</b>	13 (25.0)	1 (1.9)
<b>Previous negative personal experience</b>	6 (11.1)	19 (35.2)	<b>21 (36.9)</b>	8 (14.8)	0
<b>Medico-legal concerns</b>	8 (14.5)	<b>20 (36.4)</b>	14 (25.5)	10 (18.2)	3 (5.5)
<b>Religious beliefs</b>	11 (20.0)	<b>19 (34.5)</b>	13 (23.6)	9 (16.4)	3 (5.5)
<b>Ethical concerns</b>	0	10 (18.2)	3 (5.5)	<b>33 (60.0)</b>	9 (16.4)
<b>Institutional policy</b>	3 (5.6)	14 (25.9)	<b>26 (48.1)</b>	11 (20.4)	0
<b>Type of medical practice</b>	2 (3.6)	7 (12.7)	13 (23.6)	<b>24 (43.6)</b>	9 (16.4)
<b>Own emotional comfort</b>	1 (1.8)	10 (18.2)	12 (21.8)	<b>29 (52.7)</b>	3 (5.5)

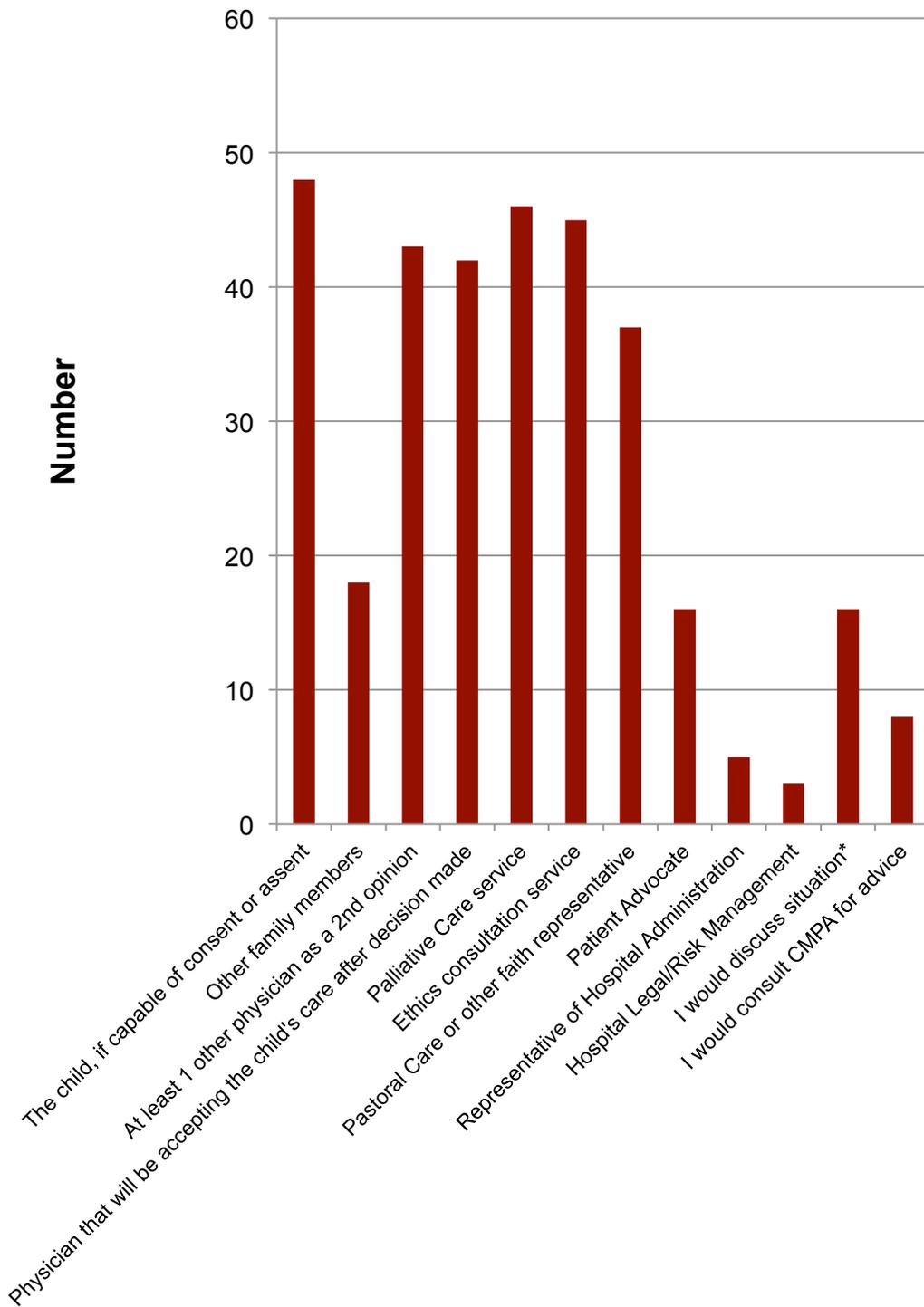
When respondents with prior experience were compared to those without experience, only “own emotional comfort” was significantly different ( $p = 0.046$ ). Compared to respondents with no experience, a larger proportion of respondents with experience disagreed or strongly disagreed that their own emotional comfort influenced their view on withdrawing or withholding IH and MPN (Figure 10).



**Figure 10.** Comparison of the influence of “own emotional comfort” on the shaping of views on withdrawing or withholding IH and MPN. \* $p = 0.046$

### Conflict

Respondents were asked which additional personnel would you consult or involve in the discussion if there was disagreement between parents and the health care team over the proposed course of action regarding IH and MPN. The results are summarized in Figure 11 with most respondents electing to involve the child (if able), a second physician, Palliative Care service, Ethics consultation, and Pastoral Care. There were no differences in the type or number of personnel involved when respondents with experience were compared to respondents without experience.



**Figure 11.** If there is conflict, who else would you normally involve in the discussion with parents and the front-line health care team? \*I would discuss the situation with additional healthcare/hospital staff prior to the meeting but I would not have them present. Respondents were permitted to choose more than one option.

## **Institutional Policy**

Respondents were asked if their institution had a formal policy or guidelines on how to address the issue of withholding or withdrawing IH and MPN. The majority of respondents (25, 47.2%) were not sure or did not know if a guideline existed (Yes: 12, 22.6%; No 16, 30.2%). For those respondents who were aware of a policy or guideline, they were asked if there was a clause in place to allow for staff to abstain from care of patients who have had IH and/or MPN withdrawn. Again, the majority were unsure/did not know (7, 58.3%; Yes: 4, 33.3%, No: 1, 8.3%).

## **Comments from Respondents**

Many respondents provided additional comments that were divisible into 2 major themes:

### ***Theme 1 – Each situation/family circumstance is unique***

“Each situation is completely unique. I regard AHN as an intervention to continue to provide comfort measures in a palliative setting. If it is unnecessarily causing distress and intervention by being present (e.g. persistent vomiting of NG tube where only hydration is being given via the tube) then recommending withdrawal is appropriate. At end of life, if families wish some AHN then that can be given with clear understanding of its role too.”

“Many times, different circumstances would change your opinion in regards a case, even though your principles dictate otherwise - how strongly the parents wish, their own ability to care for the child (risk of abandonment), etc...”

“As you indicate, this is an incredibly complex field where every situation is unique. Generally speaking, if nutrition and/or hydration is providing positive comfort for a patient, and is not unduly complex, then I would be inclined to continue, but if there is a negative aspect to its use, I would discuss and move to withdrawal. All decisions need to be made with the patient and family as



necessary.”

“It is difficult to create individual scenarios that are representative, as each situation is so different, from the medical condition and prognosis, the ability to have certainty about the prognosis, the feelings and beliefs of the parents, and others, etc. I find that I must treat each situation separately.”

***Theme 2 – Discomfort and emotion are difficult to remove from the situation***

“A good question which is never addressed due to societal discomfort.”

“Generally, where the patient is requiring another form of life support -antibiotics, mechanical ventilation, dialysis, etc - I would remove this at the same time that we were stopping AHN. It does not make sense to have a child off of all AHN while still receiving artificial life support of another kind. In my practice, the loss of this form of life support would usually lead to death before lack of hydration/nutrition. My practice and the way in which I reflect on it is influenced by past actions of our profession. It used to be acceptable for children with Down Syndrome to be denied food/water and allowed to die. It seems obvious now that this is wrong, but perhaps wasn't seen that way at the time. I am very aware that we may make life-death decisions for patients now that will be viewed in the future as barbaric. I feel quite strongly that children should be provided artificial fluid and nutrition if they would seek it out themselves if they were able.”

“This is an issue where emotions often come into play, as many view nutrition and hydration as fundamental basics of life, and not as treatments. I personally do not generally have difficulty in raising or discussing this issue, but I am very conscious of how uncomfortable it can make other members of the care team. It makes for a very difficult end of life situation if those at the bedside are not in agreement with the care plan.”

“I have been very involved in the scenario of withdrawing or withholding AHN in 10 or so neonatal and pediatric patients. I've found it emotionally draining in each case. All were parent initiated, and I agreed with the parents in all cases. However, being witness to it on a daily basis, sometimes for weeks, was horrible. Mostly related to the sense of vigil, and the marked emaciation, dehydration of the child, which was in one case almost intolerable

to behold by HCPs and parents. While philosophically I am in agreement that it is a medical treatment that can be refused, the trajectory to death is long and awful to watch. It feels different than other forms of withdrawal (i.e. NO chance for patient to survive, akin to withdrawing ventilator and placing patient in a zero oxygen environment. The outcome will uniformly be death, but over a very protracted course (many days to a number of weeks in my experience).”

## V

### Discussion

The purpose of this survey was to contribute new understanding of the factors pediatric practitioners use when considering withdrawal or withholding of IH and MPN. Withdrawal and withholding of IH and MPN is complex and filled with many ethical challenges that are magnified in children because of the rarity of the situation arising, and the strong emotional connotations surrounding feeding children and the death of children. A well-established ethical framework exists which justifies the foregoing of IH and MPN in children being ethically permissible but never ethically required. Pediatric clinical guidelines have been constructed based on this framework to help guide decision-making however, these guidelines do not reflect the difficulty in foregoing IH and MPN in actual clinical situations. In addition, since there is minimal pediatric research exploring this area, their construction has relied on extrapolation from similar adult studies and from legal decisions in pediatric PVS cases. We sought to determine which patient and practitioner factors influence the final decision, whether physicians with experience had different values and attitudes, and if what ought to be done/recommended is actually occurring in real situations. Finally, we hoped to gain a better understanding of the level of variability in decision-making because the complexity of these situations can lead to a wide range of approaches.

Children with complex medical conditions and requiring complex care continue to increase in number as advances in medical care and understanding of disease evolves. Although this translates into longer survival of these children, it also means more children are being cared for in complex, intensive care environments. Several retrospective studies

have shown that most (62-73%) pediatric hospital deaths after forgoing LST occur in an intensive care environment (105-107). Ramnarayan et al. examined deaths in hospitalized children over a 7-year period and found a rise in the proportion of deaths in an ICU setting from 80.1% to 90.6% by the last year of evaluation (108). All of these studies, despite variation in patient population, reported a majority of patients having complex diagnoses. Brandon et al. reported that 55% of children who died at their institution had at least 1 complex chronic condition with prematurity, cardiovascular disease, genetic/metabolic conditions, and oncologic diagnoses being the most prevalent (105). This was reflected in our survey as the two most frequent specialties represented in my survey were from Hematology/Oncology/Palliative Care and Pediatric Critical Care Medicine. Both Ramnarayan et al. and Carter et al. reported a higher proportion of patients with the same complex conditions (70.1% and 70% respectively) but a similar distribution of diagnoses with the differences likely due to differences in services provided at each institution (i.e. regional referral center for cardiac surgery)(106,108).

More children with complex care needs should also translate into more use of palliative care services. However, this has been a slow adoption with only a minority of patients receiving palliative care services. A cross-sectional survey examining use of palliative care services in Canadian pediatric institutions estimated that only 5-12% of Canadian children who might benefit from pediatric palliative care services received such services (109). Furthermore, of those children who did access pediatric palliative care services, the majority were referred from a general pediatric care unit (45.7%) or home (28.4%) and only 10.1% of referrals came from a critical care unit (109). Carter et al. found similar finding in their study with very few patients receiving palliative care services despite having medical conditions and reasonable durations of hospitalization before death that allowed sufficient opportunity to engage in planning for death (106).

Finding a specific reason for this slow adoption of accessing palliative care services for children with complex care needs is difficult owing to the complexity and unique features of each child, family, care teams and care environments. Likely explanations include the perception that involving palliative care services is a sign of 'giving up' on a child, a reluctance (conscious or unconscious) to give up on young patients because of the resilience of children, and the diagnostic and prognostic uncertainty of so many medical situations faced by children (3).

Difficult conversations around goals of care planning, including withdrawal or withholding of IH and MPN, are likely to increase. These conversations are not likely to be limited to pediatricians involved in palliative care, as increased utilization has not occurred to date, so other specialties, especially the critical care disciplines also need to acquire the necessary skills to navigate these difficult issues effectively. Equipping pediatric practitioners to confidently navigate the intricacies of these situations, especially, those who care for children with complex medical needs, is paramount to ensuring the right goals of care are delivered with the best interests of the patient as the highest priority.

### **Response Rate**

Only 60 surveys were returned reflecting a response rate of only 7.5% for the overall population of pediatricians in Canada. Possible factors accounting for this low rate include:

1. Inexperience with the clinical problem. Most of our responses were from pediatricians who have faced this issue. For most pediatricians, a situation where withdrawal or withholding IH and MPN occurs quite rarely and is likely the main reason for the low response rate. Carter et al. reviewed the records of 105 pediatric inpatients that received end-of-life care over a 1-year period and

found only 24 (23%) who had withdrawal of nutrition support in the last 48 hours before death (106). Earlier withdrawal of IH or MPN was not seen in this cohort. This study was limited by its retrospective, single institution nature and reliance on accurate written documentation in the chart. No additional publications have reported incidence nor prevalence of withdrawal or withholding of IH or MPN in children.

2. The theoretical or 'paper case' basis of the questionnaire. Exploring an issue from a theoretical perspective rather than exploring personal experience can be quite different and less appealing to a busy practitioner. Addressing these issues from a theoretical perspective has also hampered prior surveys on end-of-life decision-making, resulting in a wide variance in opinion (1,100,110) that may not reflect actual practice when confronted with a real situation (2).
3. Survey length may also have contributed to the low response rate. This was probably a minor contributor as participants would not have known the length of the survey and there were only 4 surveys that were incomplete.
4. We did not completely canvas the appropriate populations of pediatricians as membership in the CPS is voluntary and not all specialty groups including PCCM, NICU, Hematology/Oncology and Neurology are fully represented in the membership.

Response rates were greater in Pediatric Hematology/Oncology/Palliative Care (H/O/P) providers (24%) and Pediatric Critical Care Medicine (PCCM) providers (18%). This was a reassuring finding as these practitioners are constantly caring for children with conditions that commonly encounter decisions regarding withdrawal or withholding of LST such as IH and MPN (105,106,108,109).

Neonatal Intensive Care providers (NICU) also deal on a regular basis with decisions regarding life support and thus the very low response rate was (5 respondents) surprising, and made any conclusions about withdrawal or withholding of IH and MPN in neonatal patients less reliable. The majority of Canadian NICU providers are members of the CPS, our main source of respondents. Membership in the CPS is voluntary so not all NICU providers may have been on the distribution list. Also, we had no access to a specific NICU distribution list either through the CPS or other organizations. To further explore withdrawal or withholding of IH and MPN in neonatal patients, we would have to specifically survey this group in the future. Feltman et. al. recently surveyed neonatologists through the AAP Perinatal section exploring attitudes toward limiting LST in the NICU (100). Their survey, also web-based, had a similar low response rate of 17% but was not unexpected given the usual response in their section of 10-15%. Despite this, similar hesitancy and discomfort around withdrawal or withholding of IH and MPN was seen in this cohort at comparable rates to our findings (reviewed in subsequent sections).

## **Comments**

These situations are rare and so the majority of pediatricians may never have to experience discussing withdrawal or withholding of IH and MPN. Some pediatric specialists will have a higher likelihood of encountering these situations and this is likely reflected in our responses. A better strategy may have been to target only the Critical Care, NICU, Hematology/Oncology, and Palliative Care specialties as these respondents comprised the majority of respondents.

Overall, the response rate was below our calculated sample size of 94-108 completed surveys. This limits our ability to make conclusions overall with respect to significant factors which influence pediatrician decision-making

around withdrawal or withholding of IH and MPN. Despite this, this survey had good reliability and has yielded some important findings that will be the focus of the remainder of the discussion.

### **Case Scenarios**

This survey explored both the theoretical and actual aspects of withdrawing or withholding IH and MPN, first through case studies in a similar fashion to other surveys (16,68,100,110) and then further through questions exploring the ethical aspects and factors which may influence the decision-making in withdrawal or withholding of IH and MPN. As hypothesized, a range of opinion was seen and was reflected in the case scenarios (Tables 3-8) especially when more uncertainty (either parental, disease trajectory, or patient) was evident. A similar spread of varied opinions was seen in studies by Solomon et. al. (1)(Table 1) and by Feltman et. al (100). Averaging the answers for the 4 scenarios in Feltman's survey yielded the following distribution: refuse discontinuation of TPN, enteral feeding or hydration, 30.7%; agree with parent wishes, 28.2%; offer discontinuation with support, 18.6%; strongly recommend discontinuation, 17.7%; and defer care, 4.9% (100). Direct comparison between this study and Feltman's study is difficult because Feltman only surveyed NICU practitioners and had different response options. Despite these differences in methodology, varied opinion was seen including similar percentages of respondents (32-50% in our NICU case, Table 5) refusing or disagreeing to withdraw MPN or IH despite it being ethically justified.

The six case scenarios presented to survey participants allowed exploration of several aspects of withdrawal or withholding of IH and MPN: the consistency of responses with existing published guidelines, the effects of uncertainty and medical progress on decision-making, and the



nuances associated with both balancing the risks and benefits of the interventions and the parents' perspectives.

The scenarios represented typical medical conditions seen in children where withdrawal or withholding of IH and MPN could be considered. This was further verified in Figure 3 which showed the situations where experienced respondents encountered discussion about withdrawal or withholding of IH and MPN. Most respondents had encountered these discussions in patients with severe neurological injury (represented in scenarios 1-3), in patients with advanced, untreatable malignancy (scenarios 5 & 6), or patients with intestinal failure (scenario 4).

The first 2 scenarios examined a child with neurologic devastation; the first case was a child who met the criteria for PVS, and in the second case PVS criteria were not met. In both scenarios, the parents initiated discussion around withdrawal of IH and MPN. Case 1 had more certainty in the diagnosis and, combined with parental initiation of the IH and MPN discussion, resulted in the majority of respondents recommending withdrawal of IH and MPN. This finding contrasts an older (1992) study by Ashwal et al. in which a survey of child neurologists showed that 74-75% of respondents would never withdraw or withhold IH and MPN (69). However, our survey involved pediatric specialists outside of neurology (only 1 neurologist participated) who are also more likely to be the primary decision-maker for the patient rather than a consultant. Also, this result is in keeping with more recent studies of prognosis in non-traumatic PVS (3% at 1 year)(17,46,47) and is supported by ethical arguments concluding that MPN does not provide benefit and forgoing it is within the scope of parental decision-making authority, not inconsistent with the child's best interests (3,6).

The second scenario involved more uncertainty in the diagnosis of PVS, and despite parental initiation of discussion about withdrawal of IH and MPN, more reluctance to withdraw IH and EN was seen. More certainty was seen in withdrawal of PN, a more invasive therapy. Overall, without a certain diagnosis, prognostication is difficult, and so it seems reasonable to continue medical therapies such as IH and EN until more certainty in the diagnosis can be established.

Case 3 involved a neonatal patient with severe hypoxic-ischemic brain injury and parents who did not initiate discussion about withdrawal of IH and MPN. While the risk of developing PVS in these situations is high (47) and sound ethical arguments exist to forgo IH and MPN (3,6), respondents preferred continuing IH and MPN. There are likely two major reasons for this: a lack of parental initiation of discussion around IH and MPN probably makes practitioners less likely to recommend withdrawal/withholding of IH and MPN; and the existence of prognostic uncertainty, especially in very young patients. While arguments have been published stating that age should not be a factor in the decision (2,3), these discussions are uncomfortable (as seen in this survey, Figure 7) and most practitioners will take ample time to secure the diagnosis (6).

It is also important to emphasize that neonatologists were underrepresented in this survey. This invites the possibility that a different distribution of responses may have been seen had more neonatologists participated however a recent survey of neonatologists' views on LST by Feltman et. al. showed that respondents felt the most discomfort with withdrawal of IH and MPN (20%) compared to other LST and this correlated with more respondents refusing to recommend withdrawal of IH and MPN (22.2% - 35.7%) in the case scenarios provided (100).

Intestinal failure (IF) was the primary condition in case 4. The majority of respondents recommended continuation of all feeding interventions. Two reasons could explain these findings. First, the parents in this scenario had not indicated their goals of care whether that was withdrawal of all feeding interventions owing to the severity of the gastrointestinal injury, or exploration of long-term nutrition options in intestinal failure including long-term total parenteral nutrition and intestinal transplantation.

Second, major advances in the care of children with IF have occurred and have led to increased overall survival of this patient group. These advances have made the early exploration of withdrawal of IH and MPN in IF less common as these children can be supported long term. Intestinal failure consists of several disorders with short bowel syndrome (SBS) making up two thirds of IF cases (50,111). SBS occurs most commonly in the neonatal age group with a reported incidence of 24.5/100,000 live births and increasing risk with level of prematurity and lower birth weight (55,56). The prognosis of children with IF is improving thus increasing reluctance to withhold therapy such as IH and MPN. This is due to 3 major care advances in IF: establishment of centralized, multidisciplinary care that offers expertise in long-term PN and bowel lengthening surgery (65,111,112); improvements in both management and survival of intestinal transplant patients with 5 year survival approaching 80% (50); and better management of catheter-associated bloodstream infections (CABSI) and intestinal-failure associated liver disease (IFALD)(51,113-115).

Overall, IF has transformed into a more long-term, chronic disease in which withdrawal of IH and MPN is extremely rare and likely to occur more in a proximate death situation when there is total necrosis of the entire bowel or, more commonly, with end-stage IFALD or failure of intestinal transplant. As such, the answers given reflect this care advance in IF with

some contribution coming from the lack of parental preference in the scenario.

The final 2 scenarios involved patients with advanced, untreatable malignancies. Both scenarios looked at balancing symptom control with benefit of increasing levels of feeding intervention. There was a noticeable split in responses especially when deciding what to do with EN. This is likely due to individual respondents weighing multiple factors in each case (harm/benefit to the patient, trajectory of the disease, parental understanding and wishes, own experiences, possible other interventions to control GI symptoms while still feeding). This is an expected and reasonable approach to the scenarios as all these aspects explore the best interests of the child and each respondent will give different weights to each factor (6,42). The comprehension and wishes of the parents in each scenario also influenced decisions in these scenarios. In scenario 5, the parents were not at the same level of understanding as the medical team so it is reasonable that most chose to continue IH and EN. This probably also led to the majority of respondents choosing to not initiate PN in this patient as the possible need for surgical intervention at this stage of disease could be seen as harmful and not in the child's best interests. Parental wishes also contributed to similar results in scenario 6, but for different reasons. In this case, the parents had clear goals for feeding intervention for their child and these interventions were not harmful at this point so continuing would be a reasonable response. Conversely, one could assume that these parents were also more aware of their child's condition and may be more receptive to discussion of withdrawal of feeding interventions (whether this was the final decision or not), which could explain an equal number of respondents recommending withdrawal of PN and EN.

While these scenarios cannot represent every possible situation regarding withdrawal or withholding of IH and MPN, these cases provided a good overview of the issues faced by practitioners. Overall, consistency with existing guidelines was seen with expected drifting of responses with increasing uncertainty of the situation. Also seen was a trend to allow parents wide discretion as respondents tended to recommend continuing interventions in the cases where parents did not initiate the discussion around withdrawal or withholding of IH and MPN; again consistent with published recommendations (6), and the studies by Rubenstein and Feltman (68,100).

### **Having the Discussion with Families**

In 59% of the cases reported by survey respondents, a physician involved in the care of the child (attending, consultant, palliative care physician, community physician) initiated the discussion around withdrawal or withholding of IH and MPN. Parents initiated the discussion 32% of the time (Figure 5). The frequency of parental initiation of discussion of withdrawal or withholding of IH and MPN has not been previously reported. These frequencies would have to be corroborated by future prospective studies as recall bias probably influences our results due to the design of this study.

Why did the parents initiate the discussion in 1/3 of the circumstances? Two major reasons could account for this. First, withdrawal of any type of care continues to remain prominent in the media, especially if there is controversy or disagreement between the family and the medical team (116-121). Protracted coverage of the legal proceedings involving Terry Schiavo's family also raised awareness of care withdrawal, especially around feeding, in the public sphere (19,95,96).

A more compelling reason that has been explored previously is the reluctance of physicians to raise the possibility of withdrawal or withholding of IH and MPN due to its inherent discomfort and controversy. While there is a sound basis for pediatricians to raise this issue with families (4,6), in actual clinical situations, it is still uncomfortable and this was evident in the responses in our survey (Figure 7) and regardless of the physician's previous experience (Table 9). Part of this discomfort is still attributable to the belief that all caregivers do not see IH and MPN as medical treatment (despite significant publications to the contrary (3,4,6)). Physician discomfort with withdrawal or withholding of IH and MPN has been noted in several pediatric surveys of LST withdrawal (1,68,69,100) although the reasons why this exists were not specifically explored (but are discussed in the Review of Literature – Pediatric Research on Foregoing IH and MPN section). Even the recent survey by Feltman et. al. continued to show that respondents felt the most discomfort with withdrawal of IH and MPN (20%) compared to other LST. This correlated with more respondents refusing to recommend withdrawal of IH and MPN (22.2% - 35.7%) in the case scenarios provided (100). Both this survey and the survey by Rubenstein et. al. found an increased likelihood to frame their recommendation based on the request of the parents rather than the established ethical principles (68,100).

Feltman's survey went further than previous publications and attempted to determine what the reasons were for this discomfort. Available as an optional free-text question for respondents (the percentage who responded to this question was not reported), three main reasons were given: first, respondents raised concerns over discomfort/suffering of the child, which is not reported in adult (20,44,85,86,88,89,94) and pediatric (122) publications. Second, IH and MPN were considered more 'basic' care rather than 'extraordinary' or 'heroic'; this a common misperception reported in prior publications (3,42) as IH and MPN can be invasive and

burdensome in some situations, and cause prolongation of the dying process in other situations (42). Finally, emotional difficulty for the parents or other healthcare staff was also cited as a reason for reluctance to withdraw IH and MPN, which was also commented on in our survey.

Overall, our findings and those reported by Feltman et. al. (100) both show that continued education needs to be done to help dispel misconceptions about the perceived discomforts to children who have IH and MPN withheld or withdrawn. These misconceptions still exist today, despite exhaustive ethical, legal, and observational exploration. Physician reluctance and discomfort coupled with more awareness among parents also presents an opportunity to involve earlier consultation with Pediatric Palliative Care services that likely have more experience with conversations around the withdrawal or withholding of IH and MPN. Ongoing guidance about managing discomfort among families and other healthcare team members also needs to occur on a more regular basis. Parents will raise these issues and any reluctance to explore these issues with families will only lead to more conflict, family discomfort, and possibly providing medical intervention that may not be in the best interests of the child. Finally, development of strategies to allow healthcare team members who are uncomfortable with the decisions made on behalf of the child to opt out of care need to be more universal and widely established.

### **Attitudes, Opinion, and Experienced Practitioners**

The decision to withdraw or withhold IH and MPN in children involves multiple and complex patient, caregiver, practitioner, disease, and intervention factors. As a result, each situation has its own unique features, which can lead to a range of possible outcomes regarding the level of intervention given.

What role does experience play regarding withdrawal or withholding of IH and MPN? Our survey had participation from a large number of experienced practitioners (88% of respondents) with these situations and is the first report of pediatric physicians who have played an active role in discussing or implementing withdrawal or withholding of IH and MPN. The majority of respondents (68.5%) had > 10 years in practice and 29.6% had > 20 years in practice. Other surveys on end-of-life care and stopping LST in children have had varied participation of experienced physicians but the majority have had more representations from physicians with less practice experience (Davies et. al. – 70.4% <10 years (123), Needle et. al. – 60.8% < 10 years (124), Burns et. al. – mean years in practice of 8 years (125)).

The high number of respondents with actual experience withdrawing or withholding IH and MPN is a finding that speaks to several key aspects of the issues involved. Foregoing these therapies is contentious and difficult and involves a great amount of discussion and consultation with families other clinical colleagues. These situations are rare, but memorable, and it is compelling that practitioners who have had to face these difficult situations were willing to share their experiences. It also speaks to the need to develop more training programs for practitioners as well as to develop formal processes and supporting institutional policies that address the need for shared burdens and responsibilities among practitioners involved in the decision-making. These needs were also highlighted by the survey by Hilden et. al. who surveyed pediatric oncologists on their attitudes and practices of delivering end-of-life care to their patients. She found that despite high ratings by participants on their perceived competence in managing end of life issues, most learned to care for dying children through trial and error in practice (91.9%), from other colleagues (85.4%), or from role models in subspecialty training (81.8%) or residency training (64.5%)(15).



The large majority of respondents agreed that IH and MPN were medical treatments, should be addressed separately, and are ethically permissible to withdraw (Figure 6, 7). More variation was seen when respondents were asked if IH and MPN were ethically equivalent to other LST, and when asked about discomfort in withdrawing or withholding IH and MPN compared to other LST, twice the number of respondents were uncomfortable compared to those who indicated no greater discomfort (Figure 7). Given that almost all respondents had experience withdrawing or withholding IH and MPN, these answers are fairly representative of the role experience plays in these situations.

Examining the responses of these experienced participants actually further emphasizes the complexity and individuality of each situation where withdrawal or withholding of IH and MPN can be considered. Not only was this emphasized in some of the narrative comments, but also it was corroborated by the responses to the questions about the influence of personal and professional attributes (Table 10 & 11). Professional experiences (both positive and negative) did contribute to the shaping of respondents' beliefs about withdrawing or withholding IH and MPN, while personal experience was more ambiguous with most responses clustered around neutral. Further exploration did not yield any more specific factors that influenced our respondents. Religious beliefs were not seen as a major contributor to respondents' beliefs about withdrawing or withholding IH and MPN; however, spirituality, which can occur both outside of and as part of religion, was not specifically explored in this survey. It is possible that the influence of a respondent's spirituality may have been hidden in the choices selected in the personal experience questions. Future surveys need to account for this in their design to see what, if any, role a person's spirituality contributes to the shaping of their beliefs and whether this is different than religious beliefs.

While no pediatric studies have looked at which factors influence the views of pediatric practitioners about withdrawal or withholding of IH and MPN, Cook et. al. examined possible determinants that influence adult ICU health care workers in their decision to withdraw LST (16). In their survey, a similar variability was seen in responses when choosing level of care and LSTs in several patient scenarios. This was despite several patient factors (likelihood of current and long-term survival, premorbid cognitive function, and patient's age) being identified as important determinants to decide the likelihood to withdraw LST. The authors concluded that this variability was due to different personal values in health care providers and that this should be addressed through consensus-building forums, more policy development, and development of opt-out rules and protocols.

Both this survey and Cook's publication failed to yield a specific determinant or group of determinants driving decisions in physicians. This survey was limited by a suboptimal response rate and so the number of respondents may have been too low to detect specific and significant determinants but had a majority of respondents who were experienced and indicated that their views on withdrawal or withholding of IH and MPN were less influenced by emotional comfort or religious beliefs. These findings should have yielded other personal or professional factors that influence physician decision-making around IH and MPN but this was not seen in this survey. This raises several possible explanations, including: is there some other factor influencing respondents? Were the questions asked not specific enough to yield more detailed responses? Does the complex interaction between the child's disease and its trajectory, parent views, family situation, effects of the interventions on the child's quality of life and best interests, and views of other members of the healthcare team trump the views of the individual pediatrician and lead to the 'right' decision for each unique situation that cannot be applied broadly? The

latter question is probably the most plausible explanation, may be the actual elusive 'determinant' and is reflected in some of the findings seen when comparing opinions from experienced respondents to those who had no experience (discussed below).

Only 4 respondents (7%) agreed/strongly agreed that MPN should be given regardless of circumstances (Figure 8) despite more respondents with experience agreeing/strongly agreeing that withholding or withdrawing IH (Figure 9,  $p = 0.018$ ) or MPN (Table 9,  $p = 0.061$ ) is ethically permissible. All 4 of these respondents had experience and the finding was statistically significant (Figure 8). These are very small numbers which may mean that this is not clinically significant if a larger group was surveyed but it does raise an interesting question that deserves further study: does experience with withdrawal or withholding of MPN change one's outlook because those practitioners have seen how the trajectory of death occurs firsthand? One respondent who provided narrative comment raised this. These situations to this respondent, who agreed that withdrawal of MPN was permissible, described them as "emotionally draining", "horrible", "hard to witness", even "intolerable." Mirae highlighted similar feelings in her article (2). She provided the distinct perspective of being both a parent of a child in this situation and a health care provider. As a parent, her statements could be applied to anyone involved in a situation where withdrawal or withholding of IH and MPN is being discussed. As a health care provider, she emphasized that there is a distinct difference between theoretically discussing withdrawal of IH and MPN and actually implementing it. She also emphasized that despite understanding the ethical arguments, she was not comfortable deciding to withdraw IH and MPN on her child.

Knowing the right time and place to discuss withdrawal or withholding of IH and MPN and knowing the trajectory of death when IH or MPN is

withheld or withdrawn are important differences when comparing them to withdrawing other life-sustaining therapies. It is these aspects that could also account for the discomfort seen in respondents despite strong agreement on ethical permissibility. These aspects were not specifically explored in this survey but were alluded to in several of the narrative comments. These unique features of withdrawal or withholding of IH and MPN deserve further study as they may show a significant influence on practitioners' beliefs and discomforts around these situations.

Respondents with experience in these situations also indicated that their own emotional comfort was less influential in shaping their views (Figure 10,  $p = 0.046$ ). There are several possible explanations for this which can be attributed to having navigated the real situation: more experience with the process of dying in children, a better understanding of the "right time" to pull back interventions because of experience, a better understanding of the parents' emotional and moral states, and greater familiarity with the specific ethics publications and guidelines establishing the ethical permissibility of withdrawal or withholding of IH and MPN. Greater awareness has been seen in recent publications including Feltman et. al. where 67.2% of respondents used AAP guidelines and 40.8 – 85.9% used ethics publications or consultation (100).

## VI

### **Conclusions and Future Research**

Withdrawal or withholding of IH and MPN is ethically permissible but never ethically required in pediatric situations. Significant evolution in the ethical and legal aspects have occurred over the past two decades allowing for more detailed exploration of the factors associated with decision-making by pediatric practitioners. This survey explored those aspects and despite a small response rate, was significant in its high number of respondents with practical experience in withdrawal or withholding of IH and MPN.

While similar variation in responses was seen when presented with similar case scenarios compared to other studies examining LST and specifically foregoing IH and MPN, experienced practitioners provided useful information regarding the low impact of personal factors in their decision making and showed that experience, the patient's current state, and the discretion, understanding and beliefs of the parents take more prominence. This discretion was highlighted in spite of sound knowledge of the ethics involved in foregoing IH and MPN.

Current guidelines are largely based on theoretical ethical constructs, legal arguments, and extrapolation from adult studies rather than practical experience from practitioners faced with situations where withdrawal or withholding of IH and MPN could occur. This study adds to current knowledge by identifying the difficulties faced in actual clinical situations including the complexity and individuality of each patient and family situation which makes the solid ethical arguments less prominent, and the discomfort associated with witnessing the physical changes associated with foregoing IH and MPN which may contribute to overall physician discomfort in discussing foregoing IH and MPN.

The responses provided by experienced physicians in this survey also validates aspects of withdrawing or withholding IH and MPN that have been seen in studies looking at theoretical situations. This survey had similar response variation in the scenarios provided to respondents as reported in other publications, and also highlighted that withdrawing or withholding IH and MPN, despite being medical therapy, is different and more uncomfortable than withdrawing or withholding other LST.

Analyzing the responses from experienced pediatric physicians allowed a deeper exploration of the factors influencing their views and approaches to withdrawing or withholding IH and MPN. Experienced respondents were less influenced by their own emotional comfort and more influenced by positive and negative professional experiences. This finding needs further study, probably best done by detailed interviews of pediatricians with experience in withdrawing or withholding IH and MPN and examining more specific factors which influence their views and approaches to dealing with this topic. This type of study would also allow deeper exploration of how the patient and parental situation influences the conversations and eventual decisions around the role of IH and MPN at the end of a child's life.

The decision to withdraw or withhold IH and MPN remains complex and difficult and is influenced by many interacting aspects of the patient, family, and medical team. The ultimate goal is to make the best decision for the best interests of the child. Reliance on experienced colleagues to learn how to approach conversations about foregoing IH and MPN is an important factor that allows pediatric practitioners to navigate these conversations and decisions in a thoughtful and open manner. As care of children with complex illness advances, encountering situations where withdrawal or withholding IH and MPN may increase. Further study is still

needed to understand which aspects of the situation are the most influential and based on this survey, research should be focused on the parent perspective, trajectory of death once IH and MPN are withdrawn, and why IH and MPN are not yet seen as ethically equivalent to other LST.

Finally, development of educational materials to better train pediatric physicians, continuing to expand the role of Pediatric Palliative Care involvement in all children where IH and MPN may be withdrawn, and development of established opt-out protocols and greater dialogue to understand the views of all members of the healthcare team may mitigate some of the shrinking but still evident discomfort associated with IH and MPN withdrawal.

## VII

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## VIII

### Appendix I: Original Concept Survey (2007)

Survey: Foregoing Hydration/Nutrition in Pediatric Patients

1. Have you ever withheld or withdrawn artificially provided hydration or nutrition from a pediatric or neonatal patient? Yes/No
2. What were the circumstances?  
  
Imminent Death  
Intestinal Failure (unable to feed enterally)  
Severe Neurological Injury  
Other (specify)
3. What, if any, situations might you or have you considered foregoing artificially provided nutrition?
4. Do you consider withholding/withdrawing artificially provided feeding/hydration as a “treatment” that might be declined under specific conditions? Yes/No
5. Do you consider artificially provided feeding something other than a medical treatment, and something that all patients should receive regardless of circumstances?
6. Do you consider foregoing artificially provided hydration/nutrition as a form of passive euthanasia?
7. If parents request cessation of artificially provided hydration/nutrition, who do you think should be involved in that discussion before a decision is made? (check all that apply)

Attending physician alone

Attending physician with at least one other physician as a 2<sup>nd</sup> opinion

Physician that will be accepting the child’s care outside of the ICU setting

Palliative Care Service

Ethics Consultation Service

Nurse(s)

Pastoral Care or other representative of patient’s/parents faith

Other (specify)

8. What information do you think parents would need to know before making this decision? (check all that apply)

Parental understanding of the clinical situation

Physical appearance of their child that is likely over time with cessation of artificial feeding/fluid

Length of time likely for death to ensue if cessation of artificial feeding/fluid is mechanism of death

9. Given the strong emotions involved in perception around the issue of withholding or withdrawing artificially provided hydration/nutrition, would you ever bring up the issue with families without them having raised the issue?

Yes/No

10. Does your institution have a formal policy or guidelines for how to address this issue when it arises? If yes, please outline.
11. Does your institution have an informal guideline for how to address this issue? If yes, please outline.
12. Do you have a mechanism for staff to abstain from caring for patients who have artificially provided hydration/nutrition withdrawn if they have strong feelings against the withdrawal?

## IX

### Appendix II: Final Survey (2011)

#### 1. Default Section

##### 1. Dear Colleague:

**We need your opinion regarding the vital issues of the following survey:  
Attitudes and opinions of pediatric physicians regarding decisions to withdraw or withhold artificially-provided hydration or nutrition**

##### **Principal Investigators:**

**Mark Belletrutti MD FRCP(C), Pediatric Hematology, Oncology and Palliative Care  
Department of Pediatrics, Stollery Children's Hospital, Edmonton, Alberta  
Dawn Davies MD FRCP(C), Medical Director, Pediatric Palliative Care  
Department of Pediatrics, Stollery Children's Hospital, Edmonton, Alberta**

**Our primary objective is to explore attitudes and opinions of pediatric physicians and residents which influence their decision to withdraw or withhold tube-feeding, parenteral nutrition or intravenous hydration in neonatal and pediatric patients with serious medical conditions. This survey should take approximately 20 minutes to complete.**

**Although the survey has not been developed by the CPS Bioethics Committee, the committee feels that collecting data from Canadian paediatricians on this important subject could be useful, and as such, the CPS has agreed to help in distributing the survey to its members.**

**There are no direct benefits to your participation but this study may be able to help us understand the above primary objective. There are no foreseen risks to your participation.**

**We understand that this topic is difficult and controversial. Your participation in this survey is voluntary. You may stop participation in the survey at any time. If it is your choice to not participate, we would appreciate you logging into the survey and clicking on "No, proceed to feedback page" and at least sharing your reasons to help us understand why this topic may be difficult for professionals to discuss.**

**No identifying information about yourself will be collected in the survey. IP addresses will not be recorded.**

**This study has been approved by the University of Alberta Health Research Ethics Board. Should you have questions about this survey you can contact the principal investigators by email ([mark.belletrutti@albertahealthservices.ca](mailto:mark.belletrutti@albertahealthservices.ca) or**

**Dawn.Davies@albertahealthservices.ca) or phone: (780)407-8822. Should you have any questions about your rights as a research participant you may contact the University of Alberta Health Research Ethics Board at (780)492-0302.**

**Sincerely;**

**Mark Belletrutti MD, Dawn Davies MD**

**Pediatric Hematology, Oncology and Palliative Care**

**Department of Pediatrics, Stollery Children's Hospital**

**Edmonton, Alberta**

I consent to participate.

I decline.

## **2. Definitions**

Artificially provided hydration – provision of fluids (normal saline, dextrose solutions) through an intravenous line (peripheral intravenous line, central venous line), subcutaneous route, or feeding tube.

Artificially provided nutrition – provision of prepared solutions which contain nutrients sufficient for growth (protein, lipids, carbohydrates, vitamins, minerals). These can be delivered intravenously (parenteral nutrition – PN) or via a feeding tube (enteral nutrition – EN) placed in the patient's stomach or small intestine.

### 3. Case 1

1. A 14-year-old girl collapses at a rural school 60 km outside of the city. Upon arrival at the hospital it is revealed that she has had rupture of a cerebral arteriovenous malformation (AVM) and undergoes an emergency craniotomy. Following surgery, she remains in a persistent coma. A MRI scan at 14 days after the event demonstrates infarction of both hemispheres, suggesting that recovery will be minimal and that the neurologic prognosis is poor. After 3 months, both the Pediatric Neurology and Neurosurgery services believe that she will remain in a persistent vegetative state. The child's parents accept this prognosis and both feel strongly that their daughter would not want to live in this condition and that she really "died" in the classroom that day. They had heard about the case of Terry Schiavo in the news and ask the medical team about the option of withdrawing artificial nutrition and hydration.

While the choice of either continuing/initiating or withdrawing/withholding artificial nutrition and hydration would generally be offered to all patients/parents, how strongly would you recommend the following options?

	Strongly recommend continuing/initiating	Recommend continuing/initiating	Neutral	Recommend withdrawing/withholding	Strongly recommend withdrawing/withholding	Insufficient information to form a recommendation
Parenteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enteral feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. If the parents had asked about the option of withdrawing artificial nutrition and hydration 14 days after the event, how strongly would you recommend the following options?

	Strongly recommend continuing/initiating	Recommend continuing/initiating	Neutral	Recommend withdrawing/withholding	Strongly recommend withdrawing/withholding	Insufficient information to form a recommendation
Parenteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enteral feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 4. Case 2

1. A male infant is born at term gestation in a community hospital with unexpected cardiorespiratory depression requiring 10 minutes of resuscitation including chest compressions, intubation and one dose of epinephrine, with Apgars of 1, 2 and 8 (1, 5 and 10 minutes). Transport to the nearest tertiary Neonatal Intensive Care Unit is delayed for weather reasons, and while waiting for the transport team to arrive he develops seizures requiring treatment with Phenobarbital. He is otherwise stable during transport to the NICU. Electroencephalogram (EEG), magnetic resonance imaging (MRI) of the brain, and repeated examinations by Pediatric Neurology over the next 2 weeks indicate a severe hypoxic-ischemic injury. The prognosis is for severe neurological disability, including likely cerebral palsy and seizures. The parents remain somewhat hopeful and indicate that they would like to continue full treatment.

While the choice of either continuing/initiating or withdrawing/withholding artificial nutrition and hydration would generally be offered to all patients/parents, how strongly would you recommend the following options?

	Strongly recommend continuing/initiating	Recommend continuing/initiating	Neutral	Recommend withdrawing/withholding	Strongly recommend withdrawing/withholding	Insufficient information to form a recommendation
Parenteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enteral feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 5. Case 3

1. A female infant was born at 26 weeks gestation. Her NICU course was initially complicated by severe respiratory distress syndrome, sepsis, and grade II intraventricular hemorrhage. At 3 weeks of age she developed acute abdominal distention, bilious vomiting, bloody stools, acidosis, and hemodynamic instability. After emergency stabilization, she underwent an exploratory laparotomy which revealed necrotizing enterocolitis with perforation of the ascending colon and necrosis of most of the small intestine. Surgery consisted of repairing the perforation and extensive resection of the necrotic bowel segments. The medical team informs the parents that the baby will have short gut syndrome for which the success of future enteral nutrition is very low. The parents do not have a clear opinion about what the best course of action would be, and are looking to the medical team for more guidance.

While the choice of either continuing/initiating or withdrawing/withholding artificial nutrition and hydration would generally be offered to all patients/parents, how strongly would you recommend the following options?

	Strongly recommend continuing/initiating	Recommend continuing/initiating	Neutral	Recommend withdrawing/withholding	Strongly recommend withdrawing/withholding	Insufficient information to form a recommendation
Parenteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enteral feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## 6. Case 4

1. A 6-year-old female diagnosed with a brainstem glioma 1 year ago has a CT scan performed because of symptoms of increased vomiting. The scan shows evidence of tumour growth. She has had multiple courses of chemotherapy and full-dose radiation during the past year. No further radiation therapy can be done because she has reached her maximum tolerated dose. During her admission she is noted to have inadequate oral intake due to vomiting and increasing periods of lethargy, requiring supplemental artificial nutrition and hydration. Discussion with the girl's parents, oncology and palliative care occurs regarding discontinuation of supportive measures including artificial nutrition and hydration. The parents are surprised by the relapse and are asking about alternative therapies, even though they appear to comprehend that no further chemotherapy or radiation therapy will be beneficial.

While the choice of either continuing/initiating or withdrawing/withholding artificial nutrition and hydration would generally be offered to all patients/parents, how strongly would you recommend the following options?

	Strongly recommend continuing/initiating	Recommend continuing/initiating	Neutral	Recommend withdrawing/withholding	Strongly recommend withdrawing/withholding	Insufficient information to form a recommendation
Parenteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enteral feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



## 7. Case 5

1. A 5-year-old male was diagnosed with stage IV neuroblastoma at age 2 after presenting to hospital with a large abdominal mass. He received multiple courses of chemotherapy and autologous stem cell transplantation. Treatment was complicated by anorexia, weight loss requiring nasogastric feeding, and multiple episodes of fever and neutropenia including one admission to PICU for septic shock. A local recurrence occurred 6 months later and he received several more chemotherapy courses which were poorly tolerated. Nasogastric feeds were resumed due to further anorexia and weight loss. Chemotherapy was stopped early due to tumour progression, and comfort measures were initiated. Two weeks later, due to continued tumour growth, respiratory and gastrointestinal function was compromised with continued anorexia and intermittent intolerance of nasogastric feeding, with abdominal pain, distention and diarrhea on a daily basis. His parents have accepted that his tumour progression is end-stage, but feel that artificial nutrition and hydration should continue for now, since he remains alert and interactive with others most of the day.

While the choice of either continuing/initiating or withdrawing/withholding artificial nutrition and hydration would generally be offered to all patients/parents, how strongly would you recommend the following options?

	Strongly recommend continuing/initiating	Recommend continuing/initiating	Neutral	Recommend withdrawing/withholding	Strongly recommend withdrawing/withholding	Insufficient information to form a recommendation
Parenteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enteral feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## 8. Demographic Information

Please tell us about your practice.

### 1. Please choose an affiliation which best describes your current status.

	Area of Specialty
<input type="checkbox"/> Pediatrician	<input type="text"/>
<input type="checkbox"/> Pediatric Resident	<input type="text"/>

Please tell us your specialty if not listed in the above menu

### 2. If you are a resident, please indicate your level of training:

- PGY1
- PGY2
- PGY3
- PGY4
- PGY5
- PGY 6+

### 3. If you have completed residency training, please indicate your years of practice:

- 0 - 5 years
- 6 - 10 years
- 11 - 15 years
- 16 - 20 years
- 20+ years

### 4. Please indicate your primary practice type:

- Hospital-Based Practice with Academic Appointment
- Hospital-Based Practice without Academic Appointment
- Community Practice with Academic Appointment
- Community Practice
- Other (please specify)

## 9. Additional Demographic Information

### 1. Please indicate your gender:

- Female  
 Male

### 2. Please indicate your age group:

- 20 – 30 years of age  
 31 – 40 years of age  
 41 – 50 years of age  
 51 – 60 years of age  
 60+ years

### 3. Do you have children?

- Yes  
 No

## 10. Personal Experience

### 1. Were you previously or are you currently primarily responsible for decision-making in the care of an immediate family member with a life-limiting condition?

- Yes  
 No

### 2. Do you have any personal beliefs or values that significantly influence your professional recommendations on issues of withdrawing or withholding artificial nutrition and hydration?

- Yes  
 No

### 3. How do you think the following attributes have contributed to shaping your clinical decisions on these issues?

	Strong Contribution	Moderate Contribution	Neutral	No Contribution	Definitely No Contribution
Religion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Familial	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you chose Other, please specify

## 11. Survey Questions

### Definitions

Artificially provided hydration – provision of fluids (normal saline, dextrose solutions) through an intravenous (peripheral intravenous line, central venous line) or subcutaneous route.

Artificially provided nutrition – provision of prepared solutions which contain nutrients sufficient for growth (protein, lipids, carbohydrates, vitamins, minerals). These can be delivered through an intravenous line (total parenteral nutrition – TPN) or via a tube placed in the patient's stomach (orogastric tube, nasogastric tube, gastrostomy tube).

### 1. Have you ever been involved in the care of a pediatric or neonatal patient where artificial hydration and/or nutrition was withheld or withdrawn?

- Yes
- No
- Not sure/Unknown

## 12. Circumstances

When answering the following questions, if you have been involved in more than one situation, please consider ONE specific patient experience which you think shaped your opinions on this issue.

### 1. What was your role (choose all that apply)?

- Attending physician responsible for the patient
- Consulting physician
- Resident/Fellow
- Community paediatrician for the patient
- Provided a second opinion to the patient/family
- Physician on the hospital ethics committee

### 2. What were the circumstances (choose all that apply)?

- Intestinal Failure (unable to feed enterally)
- Persistent Vegetative State
- Severe Asphyxia
- Cerebral Palsy
- Other condition with predicted poor long-term neurological outcome
- Advanced, untreatable malignancy
- Other advanced disease state in which all available treatments have been exhausted
- Condition in which a decision to stop other life-sustaining or curative treatments occurred
- Other (please specify)

**3. Who initiated the discussion (choose all that apply)?**

- Patient
- Parent(s)
- Attending physician responsible for the patient
- Consulting physician
- Palliative Care physician
- Resident/Fellow
- Community paediatrician or family physician for the patient
- Nurse
- I do not recall
- Other (please specify)

\_\_\_\_\_

**13. Patient Age**

**1. If a patient initiated the discussion, what was the age of that patient?**

\_\_\_\_\_

**14.**

**1. What, if any, situations might you or have you considered forgoing artificially provided hydration/nutrition (choose all that apply)?**

- Intestinal Failure (unable to feed enterally)
- Persistent Vegetative State
- Severe Asphyxia
- Cerebral Palsy
- Other condition with predicted poor long-term neurological outcome
- Advanced, untreatable malignancy
- Other advanced disease state in which all available treatments have been exhausted
- Condition in which a decision to stop other life-sustaining or curative treatments occurred
- Other (please specify)

\_\_\_\_\_

15.

1. Please indicate your opinion on the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Artificial nutrition is a medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration is a medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration and artificial nutrition are distinct interventions that should be addressed separately when withholding or withdrawal is being considered.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parenteral nutrition and enteral nutrition are distinct interventions that should be addressed separately when withholding or withdrawal is being considered.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial nutrition is something that all infants and children should receive regardless of circumstances.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Artificial hydration is something that all infants and children should receive regardless of circumstances.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16.

1. Please indicate your opinion on the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Withholding or withdrawing artificial nutrition is not ethically permissible.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Withholding or withdrawing artificial hydration is not ethically permissible.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Withholding or withdrawing artificial hydration and nutrition is ethically equivalent to withholding or withdrawing other life-sustaining therapies (e.g., mechanical ventilation).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Compared to withholding or withdrawing other life-sustaining therapies, I experience greater discomfort in withholding or withdrawing artificial hydration and nutrition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In most circumstances, only the front-line health care team (attending physician, resident/fellow, primary nurse, social worker) and the parents need to be present for discussion regarding cessation of artificial hydration and nutrition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**17.**

**1. If there is conflict (parents and health care team are in disagreement over the proposed course of action regarding ANH), whom else would you normally involve in the discussion with the parents and front-line health care team?**

**Please select all that apply.**

- The child, if capable of consent or assent
- Other family members
- At least one other physician as a 2nd opinion
- Physician that will be accepting the child's care after a decision is made
- Palliative Care service
- Ethics consultation service
- Pastoral Care or other representative of patient's/parent's faith
- Patient Advocate
- Representative of Hospital Administration
- Hospital Lawyer/Risk Management
- I would not involve anyone else in the discussion
- I would discuss the situation with additional healthcare/hospital staff (i.e., other physician(s), ethics, palliative care, administrators) prior to meeting with the parents but I would not have them present
- I would consult the CMPA (or other medical malpractice organization)
- Other (please specify)  
\_\_\_\_\_

**18.**

**1. Does your institution have a formal policy or guidelines for how to address this issue when it arises?**

- Yes
- No
- Not sure/Unknown

**19. Yes to Policy**

**1. If yes, does the policy have a clause indicating the ability of staff to abstain from being involved in the care of patients who have artificial hydration and nutrition withdrawn if they have strong feelings against this decision?**

- Yes
- No
- Not sure/Unknown

20.

**1. Do any of these factors influence your view on withholding/withdrawing artificially provided hydration/nutrition?**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Previous positive professional experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Previous negative professional experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Previous positive personal (non-professional, e.g., friend or relative) experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Previous negative personal (non-professional, e.g., friend or relative) experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medico-legal concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious beliefs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ethical concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Institutional policy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Type of medical practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Own emotional comfort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Additional Comments

**1. If you declined to participate in the survey, we would appreciate you sharing your reasons for declining.**

**2. Survey participants: Please add any additional comments below.**

**3. If you would like to share your institution's policies, or if you would be interested in receiving the results of this survey please click below. You will be taken to a page separate from the survey where you can submit your contact information.**

- No thanks.
- Yes, I am interested and willing to provide contact information.