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# "Best interest" and Pediatric End Stage Kidney Disease: The Case of Baby M

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ABSTRACT

In everyday clinical practice, health professionals and parents of chronically ill children often rely on the principle of 'best interest' in the development of medically oriented treatment plans. In most cases, such processes are done collaboratively; however, 'best interest' as a standard for decision-making becomes ambiguous in situations wherein parents and health professionals fail to agree on the course of treatment. This paper will explore the potential tensions that can exist in clinical practice when 'best interest' is used for making health care decisions. The discussion will be framed within the case of baby M, a newborn child of Mennonite descent diagnosed at birth with end-stage kidney disease (ESKD). M's parents refused medically-prescribed therapy on behalf of their child because of the uncertainty of the treatment and beliefs regarding quality of life. This case highlights that the application of the 'best interest' principle in the clinical domain can be ambiguously interpreted and subjectively operationalized along a narrowly defined medical understanding of what is in the patient's best interest. In addition, this case serves as an example of how power within the health care system can be used to operationalize a medically-sanctioned definition of 'best interest', often at the expense of the values, beliefs and interests of parental caregivers.



## Introduction

For families with children diagnosed with end-stage kidney disease (ESKD), the decision of treatment modality and the timing related to the initiation of therapy is one that parents will ultimately have to contend with. In everyday clinical practice, health professionals and parents employ the principle of 'best interest' to reach treatment decisions that will most effectively meet the physical, emotional and social needs of the child. 'Best interest' in the context of this paper is understood as a standard used in pediatric health care decision making as both a guiding principle (providing direction to how decisions are made) and as an interventional principle in that it specifies under what conditions legally action becomes necessary (Ross, 2013). In most cases, such decisions are made collaboratively; however, 'best interest' as a standard principle is rendered ambiguous when the treatment goals presented by health professionals are contested by the parents of the child (Sibbald & Chidwich, 2010). Specific often to cases in the realm of pediatric care, is the ethical issue of how to weigh the social interests of the child and family against medical interest grounded in standards of care. The following paper will explore the tensions that can potentially exist in using 'best interest' as a standard principle in treatment decisions in the context of pediatric ESKD. The discussion will be framed within the case of baby M, a newborn child of Mennonite descent diagnosed at birth with bilateral renal cystic dysplasia, wherein the child's parents opted against the suggested medical treatment of dialysis and/or transplantation due to the family's cultural and spiritual beliefs.

## Case presentation

Baby M is a 10-year-old female child of Mennonite descent who resides in a rural Mennonite community with her biological parents. M's parents had initially been seen in consultation by the Pediatric Nephrology service in a neighboring community for a detailed evaluation and counseling with respect to an abnormal finding post a routine prenatal ultrasound. The ultrasound results noted the presence of bilateral cystic kidneys. At the time of testing, M's parents were informed that there was a likelihood that their daughter would be born with some level of damage to her native kidneys; however, the extent of the impairment and the implications would be unknown until her birth. As is routine practice, M's parents were provided with general information regarding the types, probable causes and treatments for children with kidney disease, including dialysis and transplant. At the time, M's father voiced that in the event M was assessed at birth as requiring some form of renal replacement therapy, the family would like an opportunity for more discussion of treatment options. The parents' initial position was that the standard treatments of dialysis and transplantation were not at the onset something they wished to consider on behalf of their daughter.

Baby M was subsequently born at 38 weeks' gestational age, and postnatal imaging confirmed the initial prenatal finding of the existence of renal cystic dysplasia. Although at birth M required respiratory

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ventilation, nephrologically she was assessed as not requiring immediate intervention for her kidney abnormalities as she had some residual kidney function. After an unremarkable six weeks in hospital, M was discharged home to the care of her parents with follow-up in place with the Pediatric Nephrology service for monitoring her kidney function and overall growth and development. M was subsequently seen every month in clinic for the first year of life and as she aged the frequency of hospital visits was adjusted to every three months. During the first four years of life her renal function remained relatively stable; consequently, M did not require renal replacement therapy. Between follow-up appointments, M's parents were responsible for ensuring her adherence to medication and diet, monitoring M's blood pressure and weight and observing that M's regular blood work was accessed by their family physician to check her kidney function. Health record documentation reflected that M's parents were very diligent in following the medically-prescribed instructions provided by medical and allied health professionals, and as a result for the first four years of life M continued to grow and develop physically, socially and emotionally.

As M entered her fourth year of life, more emerging concerns were raised with the family by the medical staff. M's blood work displayed an increasing trend that was suggestive of decreased kidney function that would necessitate the initiation of some form of renal replacement therapy. In addition, the health record indicated that at the time, there were concerns by the Nephrology service that continued decline of her renal function would place the child at negative risk with respect to her overall growth and development. Despite the concerns raised with the family, the parents were reluctant to commit to initiation of therapy in favor of continued provision of care to the child at home.

## Disease review

According to the Canadian Organ Replacement Register (CORR), at the end of 2014 there were 35,281 Canadians (excluding Quebec) living with end-stage kidney disease (ESKD). A total of 20,690 patients were on dialysis therapy, and 14,591 living with a functioning kidney transplant (CORR, 2016). There were 1430 kidney transplants performed during this same period, with 539 of these being pediatric patients. Outcomes for those receiving a transplant are positively significant: a 1 and 5-year total graft survival, 93.4% and 81. 8% for deceased donor transplants and 97.1 and 90% for living donor transplants (CORR, 2016). A diagnosis of chronic kidney disease (CKD), or end-stage kidney disease (ESKD), in the pediatric population results in significant life changes and challenges for not only the pediatric patient themselves but also for the entire family system.

For the diagnosed child, the health implications of an ESKD diagnosis can include poor growth and bone development, cognitive and physical delay, poor cardiovascular health and an overall decreased quality of life (Samuel et al., 2011; Tong, Lowe, Sainsbury, & Craig, 2010; Bercherucu, Roperto, Materanni, & Romagnani, 2016). The physical, social and emotional challenges experienced by individuals diagnosed at a young age carry forward into adulthood, as reported studies have shown that compared to their healthy peer group, individuals diagnosed with ESKD in childhood meet fewer milestones related to autonomy, social and psychosexual development. In addition, these individuals are at increased risk of experiencing emotional difficulties and poorer overall quality of life (Grootenhuis, Stam, Last, & Groothoff, 2006). Embedded in a diagnosis of ESKD is the reality that without dialysis and transplantation the outcome of death is a certainty. That said, it is important to note that dialysis and transplantation are treatments and not cures, and once initiated the cycle of dialysis and transplant is lifelong.

For parental caregivers of children with ESKD their caregiving experience is consistently reported as being a profoundly negative experience (Bercherucu et al., 2016). This parent population has been identified in the literature as being at increased risk of experiencing ongoing difficulties with anxiety, depression, psychosomatic complaints and emotional challenges related to the ongoing burden of care (Aldridge, 2008; Tong, Lowe, Sainsbury, & Craig, 2008). In addition, parents experience the physical and emotional burden of practically managing prescribed treatments, administrating medications, monitoring diet and nutrition and ensuring the child attends regularly scheduled clinic visits (Gayomali, Sutherland, & Finkelstein, 2008). Although children with ESKD are reported to experience a better quality of life post a successful kidney transplant (Goldstein et al., 2006), parental caregivers report increased difficulties in overall family functioning and quality of life (Anthony et al., 2010). Namely, the burden of care associated with pediatric ESKD has significant implications for parental caregivers in numerous tangible ways.

## Ethical decision making process

During her fifth year of life, M's overall renal function reached a critical point, and there were increasing concerns that her continued lack of treatment may result in neurodevelopmental complications, cardiac risks, anemia and subsequently an overall poorer quality of life. Medical opinion at the time was that kidney transplantation was the most viable treatment option for M, which although not without its risks, would provide her with the best odds for an improved quality of life. M's parents were educated about how dialysis may be required in the interim as a 'bridge therapy', depending on the length of time needed to find a deceased or living related donor. Through the course of several meetings with the family (who also consulted with members of their community consistent with Mennonite traditions), M's parents maintained their previous position; they did not wish to pursue dialysis and transplantation for their daughter. M's parents were fully aware that this decision would lead to her eventual death in the weeks/months that followed; however, they cited their trust and belief in God, stating that M's fate should be put in the "hands of God," and their only wish for her was to "die happily and peacefully in God's grace."

After several deliberations with the family, it became apparent to all parties involved that M's parents and the health care team held significantly opposing perspectives and beliefs regarding what course of treatment was in M's best interest. As a result, her case was referred to the Consent and Capacity Board (CCB) for the purpose of obtaining a legal ruling on what course of action was considered in her best interest. The CCB was formed and given its authority with the passing of the Ontario Health Care Consent Act in 1996 (Sibbald & Chidwick, 2010). The CCB acts as a neutral third party that adjudicates on matters relating to consent to treatment and a determination of an individual's capacity to make treatment decisions. In accordance with the role and process of the CCB, a hearing is held in which both parties have an opportunity to communicate their perspective to a selected board charged with adjudicating a ruling. In this case, the CCB was asked to adjudicate whether M should become a candidate for dialysis and transplantation in accordance with medical standards of care, or conversely if her parents had the right to refuse treatment on M's behalf, even if this decision would result in her death.

## Who are Mennonites?

Mennonite communities are of European descent, and fled to Canada and the United States in the early 1800s (Kulig & Fan, 2013) fearing religious persecution in places such as Germany, Switzerland, Austria and France. Many settled in the Pennsylvania region of the United States before moving north to Canada to claim land for farming and to build their own community. Importantly, each denomination of Mennonite congregation has its own 'Ordung', a book of rules, which functions to foster a "God pleasing life." (Kulig & Fan, 2013). Consistent with their spiritual beliefs, "members are prepared to give up individual rights and freedoms in favor of the collective good and the presentation of a faithful lifestyle" (Gingrich & Lightman, 2006, p. 186). Self-

sufficiency and labor in the servitude of God is highly valued in the Mennonite community. As a result, many Mennonite communities participate in a rural existence in which farming and carpentry are common. Community members assist each other with the day-to-day activities associated with farming, in line with their collective sense of community.

fMennonite principles of health care, as studied by Gingrich and Lightman (2006), require "a clear recognition that their cultural definitions of health and understandings of community well-being are not based on biomedical and individualistic perspectives" (p. 173). To this end, they hold the belief that to go to heaven after death, one needs to reconfirm their relationship with God in their daily life (Kulig & Fan, 2013). In this way life is viewed as very time limited, uncertain and full of vulnerabilities, but for people who believe in God, death is the beginning of their eternal life. According to their biblical teachings, an eternal life with God is achieved by living God's word, working hard and helping others while learning forgiveness (Gingrich & Lightman, 2006).

## Ethical dilemma: "best interest"

The case of baby M highlights several ethical issues that result when parents and health professionals do not share a common vision for what is the best course of treatment for a chronically ill child. In most instances in the context of routine clinical care, parents and providers seamlessly invoke the language and shared understanding of 'best interest' when coming to some level of agreement surrounding a specific course of treatment. However, concerns regarding what constitutes 'best interest' often arise when there is disagreement between what the health care team believes their obligations are to the patient and what the substitute decision maker is claiming to be best for the patient (Sibbald & Chidwick, 2010).

'Best interest' as a standard principle in health care decision making is often invoked when it becomes necessary when the person in question is deemed incapable to make personal health care decision, or in this case when the patient is of pediatric age (1–17 years) (Sibbald & Chidwick, 2010). Concomitantly, in cases where developmentally it would be deemed inappropriate for the child to provide assent to care decisions (Ruhe, Wangmo, Badarau, Elger, and Niggli (2015). 'Best interest' historically has been used as a standard in pediatric medical decision making both as a guiding and interventional principle (Ross, 2013). The challenge as articulated by Gillam (2015) is that "it has long been accepted that parent's wishes do not have total ethical or legal authority and that parent's decisions about medical treatment should be overridden in some circumstances, especially when the life of a child is at stake" (p. 9). Conversely, the definition of 'best interest' employed by the medical model has been historically rooted in evidence-based outcomes, and usually makes little allowance for competing or contradicting definitions and/or epistemological perspectives that offer a differing understanding of 'best interest'. The challenge at times for parental caregivers is that the perspective offered by health care professionals as to what is in a patient's best interest is usually understood in clinical terms with little consideration of patient values (Sibbald & Chidwick, 2010). Nevertheless, 'best interest' is inherently a question of values, as parents believe that they are making the best decision for their child (Diekema, 2004).

The literature on 'best interest' has revealed that there are various definitions of the term and different applications of 'best interest' in the context of pediatric health care decision making. Buchanan and Brock (1989) understand 'best interest' as trying to maximally promote the good of the individual. Along the same lines, Drane and Coulehan (1995) offer a biopsychosocial model of 'best interest' that depicts the principle as the foundation of a relational framework wherein there is recognition of others. Conversely, Kopelman (2007) argues that 'best interest' was never intended to be the panacea for every issue that can arise in a clinical or other setting but rather was intended to provide direction or initiate further discussion. The literature reflects that 'best interest' is ambiguous at best, and leaves it open to interpretation exactly how 'best interest' can be used to deliver optimal health care to children. As Salter (2012) contends, 'best interest' "is ill-defined and inconsistently appealed to and applied" (p. 189). As there are so many reasonable interpretations of what constitutes the 'best interest' of a child, 'best interest' "functions merely as an empty, although sometimes alluring catchphrase" (Salter, 2012, p. 190). Importantly, despite the ambiguous nature of "best interest', it has been the standard by which physician's judge parental decisions in determining whether legal or state involvement may be necessary (Salter, 2012).

It is not unprecedented for cases to land in the court system for adjudication when parents and health providers differ on what is in the pediatric patient's best interest. For example, K'aila Paulette, a 10-month-old First Nations infant from northern Saskatchewan, Canada, diagnosed at birth with biliary atresia, and a liver transplant was medically determined to be his best option for survival. After weighing the uncertainty surrounding the course of surgery, as well as the potential severe and long-term effects of necessary immunosuppressive medications, his parents opted against the surgery. The treating pediatric gastroenterologist deemed the parent's decision to deny the surgery unreasonable, and referred the case to child welfare authorities for legal intervention. A judge, after hearing expert medical testimony and the desires of the family, ruled in favor of the child and family. Resultantly, K'aila died six weeks after the ruling (Shapiro, 2005). Such highly public cases represent major value conflicts between parents and health providers, yet only a small number of these cases ever appear in published literature (Gillam, 2015). Like the K'aila Paulette case, M's case represents divergent perspectives regarding 'best interest' and the recommended course of treatment offered by the health care team to the family.

## Medical indications in the case of M

The clinical decision to initiate the standard treatment, dialysis and transplant, was supported by quantitatively derived data related to the mortality and morbidity rates of children treated with a similar diagnosis. 'Best interest' from the medical team's perspective involved the initiation of treatment so that M would not suffer and/or die from complications associated with her chronic condition. The attending nephrologist explained to the CCB that M faced a "100 % chance of death with no treatment" (physician letter to CCB, 2009). Despite the likelihood of the transplant procedure providing M with an improved quality of life, there was a recognition that the treatments, albeit standard treatment for children with ESKD, were not without their risks. The nephrologist stated that "both dialysis and transplantation have potential risks but, in my professional opinion, the benefits far outweigh the potential risks [and] transplantation and dialysis are the standard treatments in CKD/ESRD and as such should be administered" (physician note to CCB, 2009). Therefore, a definition of 'best interest' grounded in evidence supports the initiation of treatment, as it would guard against preventable death.

In the physician's decision to recommend active treatment for M, although there was no overt recognition of the burden of care that would be taken on by the family should treatment be initiated, there was a recognition that the initiation of dialysis begins a lifelong cycle of treatments. The physician noted, "a kidney transplant does not last indefinitely and in practical terms last approximately ten to twelve years although some patients have transplants that last in excess of twenty years. For a child who is transplanted in childhood they will require subsequent transplants later in life" (letter to CCB, 2009). In contrast, M's family's perspective of what constituted their daughter's 'best interest' was not grounded in evidence-informed practice but rather was guided by the spiritual and collective beliefs of their Mennonite culture.

## Family perspective in the case of M

M's parents' perspective of 'best interest' was multifaceted in nature and grounded in an unbridled sense of collective community and

devotion to the servitude of God. In large part, their perspective was informed by their faith and world view related to the role of God in their life, the afterlife and their own values and belief regarding the quality of life they wished for their daughter. For this Mennonite community, the approach to life is as an opportunity to be in the presence of God and have God present in the life of the family. Although sometimes regarded as a naïve faith in God, the Mennonite's view can instead be seen as an active submission or surrender to the will of God (Gingrich, 2016).

In a letter to the health care team, M's paternal grandfather, who served as spokesperson for the family, articulated,

> It's important to remember that our faith and religion is first and foremost in our life- our main thrust is to live within God's will." He further explained, "and the belief that God's will, should he decide to take Baby M, should be left to him without human interference as noted in the scriptures, Phillippians 1:21 –For me to live in Christ and to die is gain. While the adjustment to her condition are obviously difficult from a human or natural perspective, we as a family accept if from a Christian's viewpoint as the permissive will of God. We believe God is the creator of all life, therefore it does not behoove mankind to question or charge God regarding situations over which we have no control. Consequently, as adherents to the Christian faith we accept what God allows.

M's family was also aware of the uncertainty embedded in the dialysis and transplant process. M's grandfather wrote, "While much is trumpeted about so called successful transplants and the quality of life following, we are aware of side effects that are not publicized. There can be serious complications of a broad range including effects of anti-rejection drugs. We know of a situation where a child needed the third kidney transplant and the child pleaded to his parents to let him die. They persisted to go ahead but his quality of life leaves much to be desired." Given these statements, it would not be speculative to suggest that on some level the parents' decision to put off treatment is related in part to concerns about an uncertain outcome.

The family's position was also grounded by a belief in a specified quality of life they wished for their daughter. M's grandfather explained, "Coming from where we do and the way we interpret the scriptures and so on, the fact that there's no quality of life on earth no matter how good that would even compare with what it's like in heaven." Also, the family has specific beliefs about children and their 'best interest' in relation to God. The family's spokesperson argued, "there's nothing better for an innocent child than to go to Heaven; that's the best thing that can happen, not from the perspective of parents or the family, maybe, but that's part of our, that's the faith we have – I mean once we've grown up, we're accountable. As long as you're still innocent, you go straight to Heaven. That's what we believe, and that's, there's nothing better than that."

Baby M's family requested that M be allowed to die at home, comfortable and in the presence of her family. Her grandfather explained that,

> our position has not changed, meaning we would with assurance from our local doctor and the team at [hospital] M could be cared for and kept reasonably comfortable at home until God saw fit to call her to her heavenly home, as Jesus said John 14:2 'In my Fathers house are many mansions: I go to prepare a place for you: This is our living hope and assurance. Death will claim us all sooner or later. I quote Philippians 1:21 – For to me to live is Christ and to die is gain. We feel M to die at home among family and friends who will do their utmost to support her and take care of her she could by God's grace die happily and peacefully. This is our wish for her if God grants it.

## Contextual factors

As is often the case with ethically charged clinical situations, there are factors that need to be considered that are not immediately at the forefront of treatment discussions. In the case of baby M, one of the important considerations was the ability of the family to cover the financial costs associated with the proposed treatment. As the grandfather outlined in his letter, "We, as Old Order Mennonites, do not believe in insurance therefore do not participate in OHIP. We feel it is biblical to pay our own hospital and medical bills and not rely on social assistance. I quote Gal 6:2 'bear ye one another's burdens and so fulfill the law of Christ. The church brotherhood does help to share the cost. We question the medical profession's insistence to burden the community with the astronomical cost of a transplant." In this case, the costs associated with M's transplant included but were not limited to travel expenses, cost of medications, medical supplies and accommodation expenses pre-and post-transplant. In the case of M, a CCB ruling in favor of imposing treatment would result in a circumstance wherein the parents would be responsible for the costs associated with this life-sustaining treatment for the foreseeable future.

## Analysis

The case of M presents an ethical dilemma and illustrates the ongoing tension that potentially exists in the continued use of 'best interest' as a standard principle in pediatric health care decision making. The tensions in using 'best interest' as a standard principle are threefold: 1) the ambiguous nature of the term; 2) the narrow definition of 'best interest' adopted by medicine; and 3) the lack of recognition in the clinical arena as to the power dynamics at work in the field of medicine and how operationalizing a definition of 'best interest' often trumps the values and wishes of families in times of disagreement.

Firstly, as noted, 'best interest' is a highly ambiguous term and is therefore open to subjective interpretation by those employing the language and the context in which it is being used. Although there is no agreed upon universal definition of 'best interest', in general this concept is operationalized in terms of the proportional balance of benefits and burdens considered to be in the child's best interest (Miller, 2010). As a result, 'best interest' is often ill defined and/or inconsistently applied (Salter, 2012). According to Salter (2012), this occurs because there are so many reasonable interpretations of the term and its use "functions merely as an empty although sometimes alluring catchphrase" (p. 189). In the case of M, the differing understandings and beliefs regarding a definition of 'best interest' held by the family and the health care team could not be more polarized. In M's case, the medicalized definition of 'best interest' is derived from evidence-informed outcomes related to the previous success of dialysis and transplantation in the pediatric population. The medical consensus was that M's 'best interest' would be served by the initiation of dialysis and transplantation as they currently exist as the standard of care for children diagnosed with ESKD. This perspective is supported by quantifiable statistics related to mortality and morbidity and does reflect the potential reality that the initiation of these treatments would offer M not only survival from her disease but also an associated improved quality of life.

Conversely, the parents' operating definition of 'best interest' is informed by their values and beliefs regarding quality of life and Mennonite spirituality, believing that their daughter's 'best interest' would be more aptly served by allowing her to die in peace and to "rest with her heavenly father" (Grandfather's letter to the health care team, 2009). One perspective informed by positivistic medicine, the other by a sense of spiritually and servitude to the teachings of God. The tensions exist as both perspectives are perceived as reasonable and rationale by the parties that hold them, and neither is wrong or right by definition, just dramatically different. Such difference becomes a challenge when the decision-making process moves to the point of operationalizing one of these constructions of 'best interest' over the other.

The challenge for families who operate from a spiritual or religious perspective, if their decision involves the preventable death of a child, is that societal laws and regulations that govern "reasonable action" by caregivers will undoubtedly side with the perspective that provides

treatment for childhood disease and illness over death. This reality has implications for decision-making processes in health care, which often are articulated as 'collaborative' and 'patient-centered' decisions. Do health care professionals need to be more transparent in educating families that their values, beliefs and desires for their children will be considered in the process of medical decision making, but only if they reflect the Western medical view of 'best interest' and quality of life? At the present time, modern medicine does not permit families to allow children to die from treatable conditions, even in cases like M's in which the treatments will not result in a cure, there is no guarantee of an improved quality of life and there is a certainty of lifelong treatments.

Secondly, the working definition of 'best interest' operationalized by the health care team in this case can be interpreted as narrow in its focus in that it appears to give little consideration of the potential burden of care for the family. Salter (2012) asserts that "medical scope is limited to the child's interest only, not allowing for the broader interests of other members of the family, or the family as a whole, to enter into the decision-making process as a whole" (p. 195). In the provision of care to pediatric patients, where successful outcomes are often intricately tied to the 'wellness' of family systems delivering the day-to-day care, it is crucial to demonstrate a conscious recognition of the implications of these decisions on the health and welfare of families as a whole. Specified burdens can include the loss of the child, physical and emotional side effects of treatment, financial costs of treatment and the emotional and material burden of caring for a child during and after treatment (Salter, 2012). In the case of M, there were a number of important contextual considerations that should have been considered including the family's lack of health care coverage, their availability to meet the social, physical and emotional needs of their other children and the obligations associated with a rural existence. The potential impact of the treatment decision on M's family is significant, demonstrating how a narrow definition of 'best interest' that fails to consider all salient and contextual factors may be unreasonably demanding and unnecessarily narrow (Salter, 2012). Any decisions made regarding a child's 'best interest' should be sensitive to the child's family context, as it is the lens through which children experience the world (Carbone, 2014).

Lastly, there has been much work done on the dynamics of power embedded in the medical profession (Foucault, 1973; Jewson, 1976; Conrad & Barker, 2010). The biomedical understanding of human illness and suffering is fixed historically in medical practice, and the notion of evidence-based medicine (EBM). EMB "is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett, Rosenberg, Gray, Haynes, and Richardson, 1996, p. 71). Although in their second edition, Sackett (2000) expanded the definition of EBM to include the integration of "evidence with clinical expertise and patient values' (p.1). EBM has become a heavily relied upon tool for decision making, as it is by nature an empirically-based standard of reasonable practice and provides the illusion of certainty when used in health care decision making (Goldenberg, 2006). EBM has been found to "guide health care decision making by appealing to 'the evidence' as the bottom line is attractive to many because it proposes to rationalize this complex social process" (Goldenberg, 2006, p. 2622). The literature identifies many critiques of EBM and the certainty it claims to entail (Kuhn & Hawkins, 1963; Toombs, 1987; Gupta, 2003; Greenhalgh, Howick, & Maskery, 2014). EBM tends to minimize the existential experience of illness for patients and families in favor of more quantitatively derived outcomes. More concerning is the fact that EBM becomes the priority standard for health care decision making above other factors (Van Weel & Knottnerus, 1999). Van Weel and Knottnerus (1999) have found that when physicians make diagnoses in physical, psychological, and social terms, the EBM that is currently promoted either restricts itself to physical evidence alone, or places such evidence at the top of a hierarchy that tends to devalue any evidence 'lower down' "on the hierarchy, which typically tends to be the biopsychosocial issues associated with illness. Decision making processes that include research evidence need to use the information to expand the dialogue regarding what is best in terms of treatment options. As Greenhalgh et al. (2014) notes, "tools that contain quantitative estimates of risk and benefit are needed, but they must be designed to support conversations not climb probability trees" (p. 3).

The use of EBM has contributed also to the socially embedded power of the biomedical discourse of health and illness. French philosopher Michel Foucault characterized the knowledge/power link found in health systems as originating in the work of medicine, arguing that power is embodied in and comes with the day to day rational scientific practices associated with the work of doctors in the hospital or clinic (Foucault, 1973). The notion that the medical profession may have too much power in deciding what is or is not in a patient's 'best interest' is not new (Kopelman, 2007; Veatch, 2000). The relationship between medical knowledge as rooted in EBM and power is not in the purview of this paper, but what is important as it relates to this case is the reality that the power of the medical perspective often cannot be successfully challenged. In the case of M, 'best interest' in many ways was defined by a standard of care that was derived from EBM: the initiation of dialysis and transplantation. Standards of practice, developed out of evidenced-based empirical research, support the position that dialysis and transplantation offer a child with ESKD the best option for physical survival. In contrast, the foundation of the position held by the Mennonite family is rooted in their faith, values and beliefs regarding death and dying, and is clearly divergent from the perspective of hard science or socially sanctioned knowledge. In the case of M, this is most apparent as a decision in support of the family would translate into the preventable death of a child. Given the chasm that exists between the two positions in the case of M, it could be argued that agreement between the parties would be an impossibility and consensus on the course of treatment not attainable.

## Recommendations

The case of M is a reminder that it behooves health professionals to not only recognize the values that are embedded in individual cases where 'best interest' is being contested, but also to seek measures that enable professionals and families to mutually engage in a process to understand differences in values. Nursing can play a vital role in ensuring parents are provided a space to verbalize their values and beliefs without risk of being judged or marginalized. In cases such as this one, where perspectives of how to proceed are so divergently opposing, this becomes a real challenge. That said, nursing is uniquely positioned to provide guidance, psychoeducational support and advocacy through the decision-making process in pediatrics.

The overriding tension found in the ethical challenge in this case is essentially the same as other cases: whether the burdens and risks associated with treatment are justified by the benefits that can be reasonably expected for the child when long-term outcomes often cannot be predicated with any great certainty (Gillam, 2015). The current use of 'best interest' as a standard in ethical decision-making serves to muddy the waters rather than provide any clarity of process.

The circumstances involved in the case of M will potentially become more common in pediatric health care if one considers the changing diversity of patients and families in the context of race, culture, ethnicity and religious/spiritual beliefs. This diversity will be the impetus for treatment decision making processes that will need to be more inclusive of the values, beliefs and understandings that families bring related to health, quality of life and patient best interest. It is for these reasons that nursing and social workers alike, will have a vital role to play as not only advocates for children and families, but as conduits between patients their families and the health care system.

## Outcome

As noted, the CCB ruled (Health Care Consent Quality Collaborative, Re (W) v London Health Sciences Centre, 2009) whether the family should be made to comply with the treatment recommendations offered by the health care team or if it was within the family's rights to refuse treatment for their daughter. Upon hearing evidence supporting both positions as part of the CCB process, the board ruled in favor of the health care team. In their ruling, the CCB stated the following as the basis of their decision:

> While we had empathy for Mr. M and Mrs. M, the parents, for their beliefs, and the care and devotion they had given their child, we held that they are not acting, in this instance, in the best interests of their child. In our view, there was no evidence that contradicted the evidence of [physician} Her evidence was clear, cogent and compelling. Without renal transplant therapy, there was a 100% certainty that M would die. To allow a child to remain at home to die when there is a 97–98% chance that she would survive a kidney transplant from a family donor was not acting in the best interest of the child. The family's belief that it was better to let her die as an innocent child because they viewed life to be better in heaven than on earth was not a belief that they could impose upon M. It was clear to us from the cases cited by the lawyers (for the hospital) that the parents could not ascribe their views to the child. This four-year-old child did not have any values and beliefs. The patient's best interest were served by accepting to and adhering to the treatment plan proposed by [physician].
>
> [(Consent Capacity Board, Ruling, 2009)]

## Current health status

One year post the CCB ruling, M received a living related kidney donation from a paternal uncle. At the time of this note, M's parents have reported that she is "doing well" and has experienced several bouts of rejection that were treated with no immeasurable threat of organ loss. M's parents reported that she does not often speak about the transplant process. When questioned about decisions that will need to be made in the future if and when the transplanted kidney fails and their daughter requires a subsequent transplant, M's parents indicated that they take life "one day at a time" because "that's the way we live."

## Conclusion

The ethical dilemmas that are embedded in cases such as K'aila Paulette and baby M offer an opportunity for health care providers to pause and reflect. In no way through the presentation of this case is this writer advocating for allowing parents to make medical decisions on behalf of their children that would result in the death of the child from preventable and treatable conditions. Rather, the author is encouraging that reflection be engaged in regarding the use of 'best interest' and how a medicalized definition of 'best interest' can impose on children and families' health practices and procedures that do not take into consideration parental values, beliefs and experiences of pediatric illness. There will always be a role for EBM, but it should be used in a way that also incorporates the experience of illness, most notably as it is used in making clinical decisions regarding treatment. In continuing the discussion of 'best interest', it is important to acknowledge multiple perspectives and the power embedded in health systems to consciously or unconsciously apply a medicalized definition of 'best interest' that does not consider the child in the context of family. Through ongoing discussion, health care systems can move towards a truly patient- and family-centred philosophy of practice. Thus, agreeing with Kopelman (1997) who argued that "it is hard to use the best interest's standard in a clear way in medicine without moral, social and professional agreement about paradigmatic cases, or about the norms and thresholds to employ, does not mean that health care practitioners should stop having the dialogue both with and for parents and their children" (p.286).

## CRediT authorship contribution statement

**Andrew Mantulak:** Conceptualization, Data curation, Writing - original draft.

## References


Aldridge, M. D. (2008). How do families adjust to having a child with chronic kidney failure? A systematic review. *Nephrology Nursing Journal*, *35*(2), 157–162.

Anthony, S. J., Hebert, D., Todd, L., Korus, M., Langlois, V., Pool, R., & Pollock-BarZiv, S. M. (2010). Child and parental perspectives of multidimensional quality of life outcomes after kidney transplantation. *Pediatric Transplantation*, *14*(2), 249–256.

Becherucci, F., Roperto, R. M., Materassi, M., & Romagnani, P. (2016). Chronic kidney disease in children. *Clinical kidney journal*, *9*(4), 583–591.

Buchanan, Allen E., & Brock, Dan W. (1989). *Deciding for Others: The Ethics of Surrogate Decision Making.* Cambridge University Press.

Carbone, J. (2014). Legal applications of the "best interest of the child" standard: Judicial rationalization or a measure of institutional competence? *Pediatrics*, *134*(Supplement 2), S111–S120.

Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, *51*(S), S67–S79.

CORR (2016). *Canadian Organ Replacement Register 2016.* Available from: https://www.cihi.ca/en/canadian-organ-replacement-register-2016.

Diekema, D. (2004). Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics*, *25*(4), 243–264.

Drane, James F., & Coulehan, John L. (1995). The best-interest standard: surrogate decision making and quality of life. *Journal of Clinical Ethics*, *6*(1), 20.

Foucault, M. (1973). *The birth of the clinic.* London: Tavistock.

Gayomali, C., Sutherland, S., & Finkelstein, F. O. (2008). The challenge for the caregiver of the patient with chronic kidney disease. *Nephrology, Dialysis, Transplantation*, *23*(12), 3749–3751.

Gillam, L. (2015). Fifty years of paediatric ethics. *Journal of Pediatrics and Child Health*, *51*(1), 8–11.

Gingrich, Luann Good (2016). *Out of Place: Social Exclusion and Mennonite Migrants in Canada.* University of Toronto Press.

Gingrich, L. G., & Lightman, E. (2006). Striving toward self-sufficiency: A qualitative study of mutual aid in an old order mennonite community. *Family Relations*, *55*(2), 175–189.

Goldenberg, M. J. (2006). On evidence and evidence-based medicine: Lessons from the philosophy of science. *Social Science & Medicine*, *62*(11), 2621–2632.

Goldstein, S. J., Graham, N., Burwinkle, T., Warady, B., Farrah, R., & Varni, J. W. (2006). Health related quality of life in pediatric patients with ESRD. *Pediatric Nephrology*, *21*(6), 846–850.

Greenhalgh, T., Howick, J., & Maskery, N. (2014). Evidence based medicine: A movement in crisis? *British Medical Journal*, *348*, g3725.

Grootenhuis, M. A., Stam, H., Last, B. F., & Groothoff, B. (2006). The impact of delayed development on the quality of life of adults with end stage renal disease since childhood. *Pediatric Nephrology*, *21*(4), 538–544.

Gupta, M. (2003). A critical appraisal of evidence based medicine: Some ethical considerations. *Journal of Evaluation in Clinical Practice*, *9*(2), 111–121.

Health Care Consent Quality Collaborative. (2009). *Re(W) v London Health Sciences Centre.* (L0-08-4507/4506).

Jewson, N. D. (1976). The disappearance of the sick-man from medical cosmology, 1770–1870. *Sociology*, *10*(2), 225–244.

Kopelman, L. M. (1997). The best-interests standard as threshold, ideal, and standard of reasonableness. *Journal of Medicine and Philosophy*, *22*, 271–289.

Kopelman, L. M. (2007). The best interests' standard for incompetent or incapacitated persons of all ages. *The Journal of Law, Medicine & Ethics*, *35*(1), 187–196.

Kuhn, T. S., & Hawkins, D. (1963). The structure of scientific revolutions. *American Journal of Physics*, *31*(7), 554–555.

Kulig, J. C., & Fan, H. (2013). Understanding death and dying among the low-German-speaking Mennonites: Perspectives from a closed religious group. *Journal of Hospice and Palliative Nursing*, *15*(1), 52–59.

Miller, G. (2010). *Paediatric bioethics.* New York, NY: Cambridge University Press.

Ross, L. F. (2013). Predictive genetic testing of children and the role of the best interest standard. *The Journal of Law, Medicine & Ethics*, *41*(4), 899–906.

Ruhe, K. M., Wangmo, T., Badarau, D. O., Elger, B. S., & Niggli, F. (2015). Decision-making capacity of children & adolescents-suggestions for advancing the concept's implementation for pediatric health care. *European Journal of Pediatrics*, *174*(6), 775–782.

Sackett, David L. (2000). *Evidence-based Medicine: How to Practice and Teach EBM.* Churchill Livingstone.

Sackett, D. L., Rosenberg, W. M., Gray, J. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't. *BMJ*, *312*, 71–72.

Salter, E. K. (2012). Deciding for a child: A comprehensive analysis of the best interest standard. *Theoretical Medicine and Bioethics*, *33*(3), 179–198.

Samuel, S. M., Tonelli, M. A., Foster, B. J., Alexander, R. T., Nettel-Aquirre, A., Soo, A., ... Pediatric Renal Outcomes Group (2011). Survival in pediatric dialysis and transplant patients. *Clinical Journal of the American Society of Nephrology*, *6*(5), 1094–1099.

Shapiro, C. (2005). Organ transplantation in infants and children – Necessity or choice: The case of K'aila Paulette. *Pediatric Nursing*, *31*(2), 121–122.
Sibbald, R. W., & Chidwick, P. (2010). Best interests at end of life: A review of decisions made by the Consent and Capacity Board of Ontario. *Journal of Critical Care*, *25*(1), 171–e1.
Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2008). The experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies. *Pediatrics*, *121*, 349–360.
Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2010). Parental perspectives on caring for a child with chronic kidney disease: As in-depth interview study. *Child: Care, Health and Development*, *36*(4), 549–557.
Toombs, S. K. (1987). The meaning of illness: A phenomenological approach to the patient-physician relationship. *The Journal of Medicine and Philosophy*, *12*(3), 219–240.
Van Weel, C., & Knottnerus, J. A. (1999). Evidence-based interventions and comprehensive treatment. *The Lancet*, *353*(9156), 916–918.
Veatch, R. M. (2000). Doctor does not know best: Why in the new century physicians must stop trying to benefit patients. *The Journal of Medicine and Philosophy*, *25*(6), 701–721.