

Ethical complexity and precaution when parents and doctors disagree about treatment

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Introduction

Cases of disagreement between parents and doctors about medical treatment for children are often riven with medical and ethical uncertainty. There is ongoing debate about the right ethical framework for overruling parents: should it be on the basis of the best interests of the child (Bester. 2018), or only when parental choices would be harmful (Wilkinson and Nair. 2015)? Janine Penfield Winters' target article draws on the latter, incorporating the Harm Threshold and the Zone of Parental Discretion (Diekema. 2004; Gillam. 2016). However, she moves discussion in a promising practical direction, providing a valuable checklist to ensure that ethical reflection and consultation is unbiased and does not omit or oversimplify important considerations.

Penfield Winters mentions in passing a recent Australian case of treatment refusal (*Kiszko*). We will draw on *Kiszko* to illustrate two key points. First, that academic ethical debate can sometimes exaggerate the difference between frameworks – in most cases that reach the courts, the Harm Threshold and best interests accounts converge. Second, that ethical debate in specific cases (and careful consideration of all factors, as encouraged by Penfield Winters) might risk the loss of treatment opportunities for patients with the potential itself to cause significant harm. In those instances, there may be a need to implement immediate precautionary or protective interim measures.

The *Kiszko* case

In early 2016, the Family Court of Western Australia first heard the case of Oshin Kiszko, a five year old boy diagnosed with a rare brain tumour. Oshin had surgery to remove the tumour on 3 December 2015. His doctors, in accordance with their established protocol, recommended adjuvant radiotherapy and chemotherapy to commence within 36 days of surgery. The treatment was expected to offer a 50 to 60% chance of survival after five years. A chemotherapy-only regime offered a survival rate after five years of approximately 30% (*Kiszko 2016a*, [48]). Oshin's parents would not consent to the recommended treatment and favoured alternative therapies. Consequently, treatment did not commence.

The hospital's ethics committee convened a meeting some time prior to 16 February 2016. The committee was "a little divided" on whether there should be curative treatment or palliative chemotherapy. It explained, "the burdens and benefits equation would clearly fall in favour of giving active therapy a chance" (*Kiszko 2016a*, [31]), but some members felt that the burdens of treatment were such that palliative chemotherapy was also a valid and supportable option. It concluded that the lack of unanimity would, "suggest a cautious approach" and encouraged the

doctors and parents to continue dialogue to work toward common ground (*Kiszko 2016a*, [32-33]).

Presumably, discussions continued. On 8 March 2016, a second ethics committee meeting was held. At that meeting, the parents departed from their earlier position of wishing to *delay* a decision, to *actively rejecting* conventional therapy (*Kiszko 2016a*, [36]). Subsequent discussions did not yield any change.

On 18 March 2016, the hospital filed an urgent court application amid concerns Oshin might be removed from Australia (*Kiszko 2016a*, [5]). By the time of the hearing (24 March 2016), the tumour was “on the cusp of a massive and irreversible progression” (*Kiszko 2016a*, [45]). Doctors were unable to estimate Oshin’s chances of survival, other than to say that it would be somewhat less than the original prognosis of 50 to 60% (at [50]). The judge found this indicated “a good prospect of a long-term cure” and ordered treatment (*Kiszko 2016a*, [79]).

Tragically, the delay meant that the radiotherapy proposed for Oshin was not immediately available. Only chemotherapy could urgently commence.

Two subsequent hearings assessed Oshin’s ongoing treatment in the face of an increasingly poor prognosis. By May, Oshin’s prognosis with curative treatment had fallen to 30 to 40% (*Kiszko 2016b*, [12]). Without treatment, Oshin was likely to die within six to twelve months, although likely closer to six months (*Kiszko 2016b*, [44]). By September, long-term survival was unlikely, even with chemotherapy, and he was switched to palliative care (*Kiszko 2016c*). Oshin died on 28 December 2016.

Best interests and harm

Penfield Winters cites *Kiszko* as an example of the best interests standard being applied as the “sole framework” for decision-making (Penfield Winters. 2018).

However, the case illustrates that a nuanced judicial interpretation of best interests can converge substantially with the harm threshold/zone of parental discretion framework. The medical evidence in the first two hearings unanimously contended that it would be best for Oshin to receive chemotherapy and radiotherapy. However, in both hearings, the Chief Justice opted for a potentially sub-optimal compromise of chemotherapy. Withholding chemotherapy was perceived as harmful to Oshin and was precluded. The Chief Justice took careful consideration of the practical implications of overruling Oshin’s parents and providing treatment against their

wishes (as encouraged by the Zone of Parental Discretion Framework). His Honour did not address the question of radiotherapy in the first hearing because it was not available (*Kiszko 2016a*, [54]).

Oshin's parents strongly opposed the ordered chemotherapy. They erected a "Forced Chemo" sign above Oshin's hospital bed and refused to assist nursing staff in caring for Oshin during treatment (*Kiszko 2016b*, [13]). However, by the second hearing, their position had changed. They remained opposed to radiotherapy, but now favoured continued chemotherapy (*Kiszko 2016b*, [46]). An independent expert paediatric oncologist gave evidence that there was scope for more than one option, "based on parental preferences" (*Kiszko 2016b*, [37]). Significantly for the Chief Justice, the expert added that the "vast majority of parents" would opt for curative treatment, but that "at least a substantial minority" would opt for the chemotherapy-only (*Kiszko 2016b*, [32]).

While there may be some cases where the Harm Threshold and Best Interests standard would yield different decisions, there may not be as much distance between these frameworks as academic debate sometimes implies. One reason for this is conceptual – if harm is understood to be a "significant setback to interests" (Feinberg. 1984), then harm and best interests may simply be different sides of the same coin. Another reason is practical. Those cases of disagreement between doctors and parents that reach the courts (or ethics committees) tend to be the most extreme – involving significant concerns that parental treatment choices would cause harm.

Ethics, caution and precaution

Penfield Winters provides a think-list of factors to consider if parents are refusing medically recommended treatment for a child. However, she does not apply it to a particular case. Table 1 illustrates a hypothetical application of the think-list to *Kiszko* as it stood in February 2016.

While we do not have the specific clinical details, it appears plausible that 3 out of 5 Red Light factors could be viewed as very or somewhat likely for Oshin (treatment leading to risks of death, disability, serious complications, family fleeing). Radiotherapy following medulloblastoma is associated with a significant incidence of potentially fatal second malignancies developing later in life (Brodin et al. 2012). It is also associated with neurocognitive disability (Palmer. 2007). We assessed 4.5 of 5 Green Light, 4.5 of 5 Orange Light and 2 of 5 Yellow Light factors as "very" or "somewhat likely", while 5 of the total of 20 factors were "uncertain".

This exercise illustrates how Penfield Winters' think-list might helpfully enumerate factors to consider. However, it also points to a danger of the ethical balancing exercise. Inevitably, there

are considerable areas of empirical uncertainty. There may be scientific evidence of the survival rates for groups of children with treatment, or their rates of complications. However, it is challenging to know how to apply them to a specific child whose circumstances may be quite different.

Identifying uncertainty is important in ethical reflection. However, uncertainty can sometimes be paralysing. While the ethics committee in *Kiszko* (as far as we know) did not use this think-list, they were divided in weighing up the risks and benefits of treatment. They took a reasonable position that in the face of ethical uncertainty doctors should be cautious about seeking court permission to overrule parents. However, the concern is (at least with the benefit of hindsight) that ethical uncertainty and caution led to delays in seeking resolution of the disagreement about Oshin's treatment. Those delays meant that by the time of the first court hearing, radiotherapy was no longer available. By the time of the second hearing, Oshin's chances of long-term survival had diminished considerably.

It is obviously important in cases of disagreement to give fair weight to parents' views, to ensure that careful account is paid both to the consequences of treatment, and of imposing treatment in the face of parental opposition. However, it is also vital to ensure that careful ethical reflection does not delay timely decisions about treatment for children, meaning that they miss out on its benefit. An "ethics of precaution" means that urgent treatment may need to be provided despite parental refusal in the first instance. After treatment commencement, it may then be possible for less rushed deliberation to determine whether or not treatment should continue. That may have the additional benefit of providing answers to some of the empirical questions (including how well the child (and his parents) tolerate the treatment).

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34. (*Kiszko 2016b*)

Director Clinical Services, Child & Adolescent Health Services v Kiszko & Anor [2016] FCWA
75. (*Kiszko 2016c*)

Table 1: Hypothetical application of the facts in *Kiszko* to Penfield Winters’ Think-list⁺

Likelihood Rating	V = Very likely S = Somewhat likely N = Not likely U = Unknown/uncertain or need more information	
Think List Factor	Facts in <i>Kiszko</i> as at 16 February 2016	Rating
Green Light: Factors supporting the proposed treatment. Likelihood that treatment would:		
1. Result in complete cure (without ongoing consequences or treatments).	Little information is disclosed in the judgment about ongoing consequences or treatments. It is however, likely that there were ongoing consequences or treatments required if Oshin were to have radiotherapy.	S
2. Meet goals of the treatment team	The medical team considered that Oshin’s only chance of survival was to embark on standard treatment and that the “vast majority” of parents faced with the same agonising choice would opt for a curative approach. They considered that Oshin’s chances of survival were higher than the potentially long-term burdens (<i>Kiszko 2016a</i> , [40]).	V
Meet goals of the family	It is difficult to identify with certainty the goals of the family. Naturally, we assume that they did not want Oshin to die. However, they did not want Oshin to experience trauma from treatment. Consequently, the parents wanted to try alternative treatments based on nutrition. However, the mother (and the father) did not view the natural therapies as a cure (<i>Kiszko 2016a</i> , [37]).	N/U
3. Reduce or eliminate unpleasant symptoms – short term	Presumably the chemotherapy and radiotherapy would slow growth of the tumour in the short term.	S
Reduce or eliminate unpleasant symptoms – long term	The chemotherapy and radiotherapy was more likely than not to cure the cancer.	S
4. Improve the child’s ability to enjoy activities of childhood	<p>If the question is directed at an assessment post-treatment, then the answer would be somewhat likely, given that Oshin’s prognosis if the treatment was commenced when recommended was 50-60%. If Oshin’s survives, then the answer is very likely.</p> <p>If the question is directed to Oshin’s experience during treatment, then answer is lower likelihood. We assume the question is directed at the outcome of the treatment.</p>	V/S
5. Improve child’s ability to participate in home & family life	The same as question above applies.	V/S
Other benefits - list	The treatment offers Oshin the best and only chance of saving his life. Based on a prognosis of 50-60%, it is more probable than not that Oshin will survive. The Chief Justice expressed this as a “good prospect of a long-term cure.” (<i>Kiszko 2016a</i> [79]). The alternative treatment option of chemotherapy only is not curative, and unlikely to save his life. The family’s preference for alternative treatment is considered unsupported by scientific evidence and not rational (<i>Kiszko 2016a</i> , [38]).	
Red Light: Unacceptably bad sequelae of proposed treatment		
1. Treatment itself could result in death or serious permanent disability	Radiotherapy following medulloblastoma is associated with a significant incidence of potentially fatal other malignancies (eg lung/stomach cancer) developing later in life (Brodin et al. 2012). It is also associated with	V/S

(suggested threshold >1 in 200, dialogue on threshold encouraged)	<p>neurocognitive effects (Palmer. 2007). However, likelihood and severity of occurrence is difficult to assess for a child who has not commenced treatment within time recommended in established protocol.</p> <p>In the second hearing, His Honour set out comprehensively, evidence from an independent expert in paediatric oncology about the risks and nature of long term side effects of radiotherapy. These side effects were not immaterial, but were dose dependant. They included possible cognitive and intellectual impairments which were said to be more limiting than possible physical effects (which included reduced lineal growth, hormone deficiencies, hearing loss, persistent dizziness and tinnitus) in the integration of cancer survivors into mainstream society (<i>Kiszko 2016b</i>, [24]). The evidence explained that the extent of the impairment could be significant in some cases but in others, might not necessarily result in a reduced cognitive capacity below the lower end of the average range for many patients. Other long term consequences included reduced likelihood of employment and ability to live independently (<i>Kiszko 2016b</i>, [21-39]).</p>	
2. Complications from treatment could result in death or serious permanent disability (anaesthesia, surgery, sepsis, clot, stroke, bleeding, errors etc) suggested threshold >1 in 100, dialogue on threshold encouraged)	Severe complications from radiotherapy and chemotherapy are possible (eg overwhelming sepsis related to myelosuppression). However, likelihood and severity of occurrence would depend on the protocol used.	S
3. The proposed treatment is newly incorporated, unproven, or likely to change.	The treatment proposed was conventional therapy typically recommended for medulloblastoma cases involving children of Oshin's age. However, its effectiveness in a case involving a child whose the treatment had been delayed beyond the time recommended in the established protocol was unknown.	U
4. Permanent separation of child from family due to treatment	No permanent separation required.	N
5. Overriding parents may result in serious setback to child's interests (family flees) or unusual risks (delays, restraints)	<p>This was largely uncertain as at 16 February 2016, but by the time of the first hearing (24 March 2016), there was some concern that the parents might flee with Oshin.</p> <p>As an aside, after His Honour ordered the chemotherapy, the parents were compliant in bringing Oshin to hospital, but placed a sign above his bed that read 'Forced Chemo'. However, they removed this sign when the second cycle commenced (possibly after forming the view that its adverse impact on Oshin was less severe than they perceived and/or after learning that Oshin was responding positively to chemotherapy). By the time of the second hearing (16 May 2016), the parents were in favour of a further two cycles of chemotherapy treatment.</p>	S
Orange Light: Likelihood of serious drawbacks or burdens		
1. Extended treatment duration or more than one episode of care	Oshin's treatment required more than one episode of care.	V
2. Relapse or re-occurrence expected	Recurrence in childhood medulloblastoma is somewhat likely, though hard to estimate in Oshin given the delay in adjuvant treatment.	S
3. Pain, symptoms or suffering DUE TO treatment – weight by severity	The medical team did not express a likelihood of the symptoms occurring or their severity/duration, but considered that the burdens were outweighed by the benefits. There was division amongst the hospital's ethics committee about the extent to which these burdens were outweighed by the prospect of a long term cure. However, after the first meeting, they found that curative treatment should commence.	S
Pain, symptoms or suffering DUE TO treatment – weight by duration	Same as above.	U
4. Other burdens to child – during treatment	Emotional distress, particularly caused by Oshin's fear of blood, and ongoing distress in seeing chemotherapy port in his stomach, resulting in refusal to shower and bathe. Distress also possibly from influence of the parents' highly vocal and strong views that his treatment was 'torturous.'	S

Other burdens to child –after treatment	Long term adverse effects from treatment were of significant concern.	V
5. Requires parents to participate in treatment on an ongoing basis, including care for implanted device, or lifelong treatment requiring active family participation.	Oshin would require ongoing care in hospital and at home. The need for lifelong care is less certain, and highly variable. Long term survivors have varying degrees of independence and needs in managing any longer term side effects. Many go on to live independent lives without the need for ongoing treatment, others do not.	S
Yellow Light: Caution		
1. Separation from child from home environment for more than 1 short episode	Typically the treatment involves multiple hospital stays.	V
2. Likelihood of serious burdens to parents/siblings due to treatment.	The parents initially cited these types of concerns as reasons for refusing the treatment. At the first hospital ethics committee meeting, the mother had explained that she suffered from chronic pain, which was important to the care that Oshin would need away from the hospital (<i>Kiszko 2016a</i> , [26]). She also set out concerns from her own life experience with close family who had suffered and died from cancer (<i>Kiszko 2016a</i> [28]). The father was on unpaid leave and in the event that there was significant impairment over the six month period of treatment, it would be difficult for the father to provide support at home (<i>Kiszko 2016a</i> , [27]). However, after Oshin had completed two cycles of chemotherapy, they were prepared for Oshin to have a further two cycles of the treatment and did not press any further concerns about further burdens on them. It is not clear if their personal circumstances had changed, if the impact on their situation was less severe than they had initially anticipated, or if the same burdens remained, but had become more tolerable for the parents.	S
3. Overriding parents expected to have negative impact on the child, siblings and family stability	This was uncertain as at 16 February 2016.	U
4. Overriding parents has negative impact on a sub-culture or community of which the child resides (loss of trust leads to decreased access by community).	This was uncertain, but probably unlikely, however parents did embark on an active media campaign, which resulted in the hospital (at the second hearing) seeking a court order that the parents not identify individual doctors or disparage the hospital.	U
5. Treatment proposed not available in family's subculture and cannot be continued once family returns to their home culture (eg. international visitors).	Not relevant to the circumstances.	N

⁺ Assessment based only on facts as at 16 February 2016, as reported in the Chief Justice's reasons for decision dated 24 March 2016. Clinical and other information was not provided.