



Reflections on Refusal of Treatment

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Introduction

Ethical and legal dilemmas develop when parents refuse promising medical treatment for their sick child. Challenges facing medical professionals are amplified further if the family has a different cultural or religious belief to those of professionals. An ethical framework is needed in this challenging situation because it can find a way forward by helping decision-makers take a step back and weigh the probable harms and benefits of their options. This article will analyse the Tovia Laufau case in terms of possible effects of treatments, clinicians' duties, the Laufaus preferences, Tovia's rights, and then discuss its legal, ethical and clinical implications.

Case Presentation

Tovia Laufau was a 13-year-old Samoan boy who had a malignant tumour on his leg. The paediatric oncologist who made the initial diagnosis said that he told the parents, there was a 60-70% chance to recover if Tovia treated with surgery and chemotherapy [1]; without treatment, Tovia would die. The Laufaus said they needed to talk to other family members to decide what to do and they would tell their decision to the doctor the next day. However, they never sought any medical care after then. Six months later, Tovia died from malignant metastases. At post mortem, the suppurative tumour on his leg weighted 15kg. Tovia's parents were subsequently convicted of "manslaughter and failure to provide necessities of life", and each received a 15-month suspended sentence [2].

Parental refusal of recommended treatment

The recommended treatment options could palliate Tovia's symptoms and improve his survival, but it could also cause numerous short-term and long-term side effects. Surgery, for example, it could cause amputation which itself carries its own side effects such as residual limb pain, skin infection, long-term intensive physical rehabilitation and psychological therapy. Moreover, more surgeries would be required in the following years due to bone grafts or prosthesis replacement [3,4].

Chemotherapy usually used prior to and after surgery to improve the prognosis of the patient. Due to administration of powerful medications during this therapy, Tovia may lose hair, suffer anaemia, nausea and vomiting, fatigue, abnormal bleeding, liver diseases, kidney failure and a higher risk of severe infections because of an undermined immune system [5].

For Tovia, losing a leg could be the most terrible and harshest consequence of cancer. He had to say goodbye to rugby. He must suffer amputation pain and phantom limb pain day and night. He also needed increased effort or other people's assistance to do daily activities. These physical issues and inconveniences could cause many emotional issues. For example, Tovia must cope with being "different" and suffer emotional distress due to the change in body image and restricted physical activity.

His parents must spend more time to take care of him, and thus spending little time on Tovia's sister. The treatment and reduced working time might impose a financial burden on the family. Moreover, Tovia's parents and sister would also feel distressed and grief about the loss of Tovia's health.

Worse, with the proposed treatments, the overall 5-year survival rate for Tovia is around 30% as the tumour has spread to his lungs at diagnosis [6]. From the family's point of view, all the efforts and suffering might be ultimately meaningless. They still had a higher risk of losing Tovia even they endured so much.

Ethical dilemma

The ethical dilemma for the case of Tovia was a collision between medical providers' obligation to 'do good' and parental authority, and the involvement of young teenager's rights make this dilemma more intractable.

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fatigue, and accompanied considerable with side effects, but without those treatments, Tovia could soon die; c) there are no less intrusive options for prolonging Tovia's life. Tovia and the Laufaus did not think accepting treatment in the best interests of Tovia, and thus rejecting treatments [9]. Medical providers cannot provide obligatory treatment when patients refuse (unless limited exceptional situations defined by law) because they not only have a duty to care, but also have an obligation to obtain informed consent from patients or their surrogates.

Objective: Informed consent is an essential outcome of the respect of autonomy. It refers to the patients' agreement or approval of any medical procedure to be done to them. Seeking information consent is not an act, but a process which encompasses three essential components: information, voluntariness and competence.

Medical providers must ensure that all relevant information is provided in ways which are proportional to the patients' level of understanding. Reflective conversation with medical providers is the only way to know if they understand the provided information. Since the agreement to treatment must be voluntary, we are only permitted to persuade them without coercive elements. This principle presumes that patients or surrogates are competent to make a specific treatment

the trust relationship was not built. Further, this was the first time that the Laufaus had faced such a big decision for Tovia at a time when they are highly stressed and grieving. They did not want Tovia to die. They just chose the wrong methods. This might be morally justifiable. However, it is extremely hard for a morally compelling excuse to outweigh the basic rights of the minors.

The vulnerability nature of the children and the young people make them enjoy substantive rights, in addition to participation in the process