

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 pediatric 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 weighed 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].

Possible effects of recommended treatments

The recommended treatment options could palliative 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 anemia, nausea and vomiting, fatigue, abnormal bleeding, liver diseases, kidney failure and a higher risk of serve 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.

Physician's duties

Beneficence: In biomedical ethics, beneficence is the principle that captures an obligation to do good or what will contribute to the patient's welfare when other things being equal [7]. Typically, the principle of beneficence corresponds to the virtue or human character traits of benevolence.

This principle requires us to weight or balance the potential benefits and burdens of an option, then taking positive steps to protect patients and their families against undue harms while maximising possible benefits and minimising possible risks. The corollary is that it is morally wrong not to promote the benefits of others when we are knowingly in a position to do so. However, that does not mean medical providers should do all well and avoid all harm. They are generally required to do actions which could produce more benefits than burdens.

Utilitarians like Mill argue that the single standard of beneficence could coherently unify a bunch of incompatible moral theories and thus helping we decide the rightness of actions objectively. Actions are right if they produce the greatest balance of good over harm, are wrong as they produce the reverse. Therefore, beneficence is an outcome-based principle.

The principle of beneficence rests on the importance of what is in the best interests of the patient. Due to cultural bias and errors of omission, patients and medical providers sometimes have conflicting perceptions of 'best interests' [8]. In medical practice, this divergence is the root cause of the conflict between "doing the good" and "respecting for autonomous decision-making" despite the complementary nature of these two principles.

In this case, from a clinical standpoint, providing Toiva with necessary treatment has more pros than cons. Three reasons for this: a) surgery and chemotherapy are typical treatments for osteosarcoma and proved to be efficacious; b) the treatment might be lengthy,

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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.

Obtaining informed consent: 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 decision based on [7].

Obtaining informed consent is intended to be not only a moral but also a legal safeguard for respecting the autonomy of the patients. It is an external expression of medical providers' pivotal ethical duty to support and improve their patients' autonomy. Self-determination on treatments that they do desire rather than ones they do not desire, giving them a sense of self-respect and dignity.

The legislation relating to informed consent is constructed around those who fit into a mainstream habitus. It is possible to see a conflict between the patients' or surrogates' informed decision against recommended treatment in accord with their best interests.

The Tovia case is such an example. The oncologist told Tovia and his parents that surgery and chemotherapy are requisite and effective in prolonging Tovia's life, and Tovia would die without them. The low survival rate, as well as lengthy, complicated, fatigue, painful treatment process was alarming and distressing for Tovia and his parents. Tovia and his parents did not return hospital for treatment after the oncologist providing them with the relevant information. The oncologist clearly knows that this was not in Tovia's best interests as both his life and quality of his rest life would be severely diminished.

The first dilemma for medical providers is the conflict between the obligation to do good (offer treatment) and respecting the autonomy of Tovia and his parents (not offer treatment). If Tovia was over 16 and competent, we must respect his refusal of treatment, even death would occur because of his action. That is the legal significance of informed consent. So the ethical dilemma here is the following: what should medical providers do if there is a conflict between an incompetent patient's autonomous preferences the same patients' own best interests? Simply stated, is Tovia, as a 13-year-old teenager, competent enough to refuse consent to life-preserving treatment?

Is Tovia mature enough to make a life-or-death decision? When the child's preference has a conflict with his/her best interests, cautions must be observed to make sure that the principle of beneficence is not indiscriminately applied to override the desires and welfare of the child. In NZ, the Code of Health and Disabilities Services Consumers Rights is the legislation that affects the minors (< 16 years) 's rights to consent to health issues [10]. The Code is in keeping with an approach

that highlights self-determination to the fullest possible extent. Within the Code, regardless of ability to consent, young persons are allowed to participate and consent in making decisions influencing themselves at a level in accordance to their maturity and understanding unless there are sufficient reasons not to do so. When a young person achieves a sufficient level of competence, their viewpoints must be treated as decisive.

The Code also provides young people with a competency assessment which is governed by the objective guidelines. When the minors proved not incompetent, consideration is afforded the best interests of the minors, and the views of their proxy decision-makers (usually parents) would be taken seriously. However, it is still good practice to obtain the consent of parents even if the child is competent because this approach respects parents' natural wish and cultural practices.

The young persons are more mature, socially and sophisticated than in the past, but the legislation failed to respond to their development. It is not enough to adopt the age test and the Gillick competency test within the existing statutory scheme. The status-based test is flawed because it overlooks the fact that the minors are autonomous, intelligent beings before their 16th birthdays. Understanding-based Gillick competency test is more complicated and needs more reasonable judgement that does an age test.

Tovia was not provided with the competency assessment as he did not appear after diagnosis. Even if Tovia received the assessment, it is still difficult to determine whether Tovia has sufficient understanding and intelligence to be capable of self-determination because of difficulties in applying the competency tests. Moreover, to make an optimal treatment decision, Tovia must weigh benefits and harms of treatment and understand the full range of implications that his refusal of treatment on his life, religious beliefs, values, family members, and other factors [7]. Tovia might be competent to consent to the setting the bone, but he might lack the requisite understanding and maturity to make a life-or-death decision. As said by Beauchamp and Childress, standards for the competence of the minors should be set higher in cases where the consequences are severe or involved treatment with high levels of risks [7].

Thus, at this stage, it seems reasonable that the oncologist's offer of treatment trumps Tovia's refusal of treatment. However, the conflict is not over as his parents also reject treatment. As we said before, parents are legally allowed to make decisions on behalf of their child. Then another dilemma develops: can the parental refusal override the right of their child to receive life-preserving treatment?

How loving parents balance their rights and duties? Tovia told his parents he did not want treatment, and his parents gave evidence that Tovia thought he would die 'straight away' if he went back to the hospital. They also said that Tovia twice tried to jump from a moving car to avoid going to the hospital for treatment. If they force their son to receive treatment, their son might hurt himself. Moreover, even receiving painful and terrible treatments like amputation, his son would still suffer a higher risk of death. If they did not do so, their son might get their care in a relaxed family atmosphere. Additionally, they though Tovia was mature enough and fully understood what would happen without treatment. More importantly, they strongly believed that God would provide healing for Tovia. Thus, they decided to accede to Tovia's bidding because of their love of Tovia.

Medical providers could see the picture clearly and they did what they supposed was essential to convey this to the Laufaus and Tovia. Due to the language barriers and medical jargons, it was hard for the Laufaus and Tovia to understand what was happening. It was clear that

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 of information sharing and provision of views on medical procedures, they also have the right to be 'protected from harmful influences, abuse and exploitation' [11]. These rights create parallel duties for parents. Parents must provide with necessities for their children, and this might include making decisions in the best interest of their children.

This legally defined good parenting required Tovia's parents to accept the proposed medical treatments, persuade and encourage Tovia to receive treatment and help with the care of Tovia. However, they did not do those. Tovia's disease only can be stemmed or alleviated by medical procedures, but they put their faith in God. Their decisions made Tovia die without any medical care. The last six months of Tovia's life might full of pain, tears and fears.

Possible Actions in this Case

Tovia should be referred to palliative care at the time of cancer was diagnosed. Then clinicians should conduct a timely assessment to gather Tovia and his family's information such as their experiences, needs and expectations and burdens, cultural and spiritual values. Then physicians could make a tailored care plan to address the Tovia's physical, emotional, social and spiritual dimensions of suffering based on gathered information. When the family disappear, physicians should use resources such as social work, counselling, cultural support, financial support to persuade the family of the need to accept the recommended treatment. If the dispute could not be resolved, the physician could seek legal resources to override the refusal of treatment. However, the medical provider in Tovia case did not seek a treatment order as Tovia was found to have the metastatic disease which could significantly decrease the chance of cure [12].

Conclusion

Respecting the rights of the minors as individuals is vital in affecting the ways we treat them. However, the minors do not exist in isolation. They live and develop within complicated contextual environments. Their developing sense of identity and uniqueness is entwined with the relationships they have with their parents and cultural or religious beliefs in their community. Thus, there is no way to consider consent problems without thinking about the above factors and recognising the sometimes conflicting views of the person involved in a young people's

life. Failure to establish a trust relationship with the family and the patient could cause unintended serious consequences, just like in the case of Tovia.

The relationship between the medical providers and the patients represents the front line of the provision of medical care. It plays a vital role in determining whether our medical care can obtain good ethical outcomes. Thus, in order to avoid this tragedy in the future, we should build a stronger trust relationship with patients and their family.

This demands us to treat them as equals, understand their needs, perceptions and worldviews. Timely conversations and negotiations about the patient's desires or perceptions of what does and does not count as goods to be chased or burden to be avoided is an optimal way to gather information. With this essential information, we can make the least controversial treatment regime in line with the interests of the patient and is agreed by the patients. This is a long process and needs empathy, patience and kindness, but it will be worth it if it means that medical providers and families can collaborate to save more young lives.

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