

Autonomy Overrides Professional Obligations! An Ethical Analysis

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ABSTRACT

Autonomy is considered the prime principle in medical ethics. Health care providers (HCP's) are obligated to respect patients' autonomy in almost every situation. Even if patients' take decisions that poses could threaten their life. It is especially challengeable in case of children where the key decision-makers are parents. This paper identifies such conditions in which there is a conflict between the parents' autonomy to make decisions on behalf of their child and beneficence to improve children's health. A question arises with this situation on that, is it right to respect parent's autonomy or not, but HCP's are committed to do in the best interest of their patients.

Keywords: Autonomy; Health care provider; Children; Parents; Beneficence

SCENARIO

This paper is based on a Scenario of a newborn baby who was born with spina bifida. The health Care Provider (HCP) told the mother about the condition of her child and arranges a meeting with both parents. During the meeting, the HCP explained about the possible risks and the benefits of successful surgery on child health. But parents were refusing from surgery and wanted to go against medical advice. However, HCP discharges the child and the couple left the hospital. Two weeks later, the mother brought her child with a serious condition. The sac was ruptured and the child developed high-grade fever and hydrocephalus. The child was immediately shifted in the intensive care unit. After one week, the child expired.

In health care organizations, ethics is the basic tool to measure the standard of care. Every health care provider is obligated for the implementation of ethics in their practice. This takes special consideration, especially when dealing with children. As children are the most vulnerable group of our society and due to their incompetence, parents are the natural caretaker who ensures all the basic needs of their children are met.

While dealing with the care of children health care professionals frequently come across such ethical conditions in which parents' decisions/autonomy often cause dilemmas. The same has occurred in the above scenario, where parents' autonomy overrides HCP's beneficence towards the child. Parents are

considered best surrogate on behalf of their children. Parent's autonomy on behalf of their child is always respected but conflict arises when their decision regarding child treatment exposes the child to a serious threat which ends up in irreversible complications [1].

1ST POSITION (FROM THE LENS OF HEALTH CARE PROVIDER)

HCP's are always committed to do in the best interest of their patients. As every physician swear to stick the oath with honesty and this is "...I will apply, for the benefit of the sick, all measures which are required..." [2]. In the care of children, parents are the key decision-maker due to the inability of the child to make a decision. HCP's are responsible for obtaining the informed consent of parents. They should be conveying the full information regarding treatment, alternatives, side effects, benefits and future threats of health towards children. They are even responsible to judge the parents' understanding and do cross-questioning to evaluate their decision-making capacity. The aim should be to help parents in making a decision that fits the best interest of their children by keeping in mind all principles of ethics [3].

In our case, parents' refused the surgery which had affected the child's survival. HCP did not assess why parents took such a decision? HCP should analyze that parents' have the competency of decision makings influenced by their misunderstanding or

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faith regarding surgery? HCP simply thought to follow the principle of autonomy, of parents having full authority to take a decision regarding their child's life or even death. Here, HCP did not feel the need for further communication sessions with the family. There are many factors that may affect such kind of behavior. This may be due to a shortage of time, the high burden of patients, and simply due to incompetency in communication and counseling skills. There may be cultural restraints in which they feel the pressure of violence and threats from family due to the unpredictable consequences of surgery that restricts them to further counsel the parents. There may be a threat of being blamed if surgery went unsuccessful. HCPs' role in decision making of parents governed around three hallmarks of informed choices. First to provide detailed information regarding the disease, treatment, affects, future problems, and complications in a simple and understandable language according to parents' level of education, and competency to understanding. If communication and information are given properly this will empower the parents to evaluate risks and benefits realistically and finally take a suitable decision without any manipulation and coercion. Even if the health care provider feels that decision is not appropriate according to child condition there are other options to further evaluate and conduct sessions to change their mind and help them to take an appropriate decision. HCPs' can contact the ethical committee of the hospital and go for other resources of child protection services and court if the conflict does not resolve but it should be kept as last option which I feel in our case is the deficiency from HCP [4].

2ND POSITION (FROM THE LENS OF PARENTS)

Parents are always doing their best for child health and wellbeing, and strive for doing everything with their heart. Their sincerity towards their child is matchless. On the contrary, there are circumstances in which their decision should not be considered ethically justifiable in accordance with child interest. A number of outcomes should be considered to make a rational choice including considering the chance of survival, quality of life with or without treatment, evidence-based evaluation of immediate and long term benefits and risks to the children [5]. Immediate and long-term effects of treatment on child quality of life and justification of effects is important if not taking the treatment. Such considerations, when applied fully, empower parents to make a decision that a rational person will take in such condition and that can be justified. As Kopelman said in this regard if parents fail to understand in taking a decision in the best interest of the child and there is a serious threat of child health state should interfere and the court should decide what is in the best interest of the child [6]. If we analyze it in the light of Fiqh, it says that "parents or legal guardians are obligated to have only the child's best interests in mind and not reject measures upon which the child's life depends within reasonable limits, as this is the responsibility they have been charged with the child" [7].

There are a number of factors that affect their capability to take a justified decision. These may be family pressure, disease process of the child, breaking the dream of a perfect child, inadequate knowledge regarding child treatment, lack of

understanding and ability to weighing the benefits and risks of treatment and past family experience regarding surgery. All these factors affecting their decision capacity and often they take a decision that exposes their child to the risk of death [8]. In our scenario, it was found that their decision regarding treatment was not morally appropriate. As it was an impossible and unrealistic goal for them to provide lifelong care of a child with spina bifida. Surgery is necessary, as the sac ruptures and infection introduces in the body, there would be more complications, a threat to survival and quality of life would be compromised.

JUSTIFICATION OF MY POSITION

My point of view is that as an observer of the whole scenario I feel that HCP's did not play their role adequately. As parents' decision regarding surgery was not rational which exposed the child to a serious threat. It is evident by literature that surgery is necessary for child survival and without surgery; children do not survive more than 6-12 months [9]. This is not simply a case to respect the parent's autonomy; it is the matter of survival of a child. The health care provider should review the case when he knew that parents do not agree with the surgery and realistically evaluate their decision in the best interest of the child. When he found that there is a threat to child health he should consult with other members of the health care team. HCP could have counseled and tried to identify the reason behind parent's decision, whether there is a gap in knowledge, analyzing benefits and risk, or they might have any past experience which could influence parents' values and beliefs regarding child health. If any of the reasons were found behind their decision, it could have been sorted out through reassurance and counseling [6]. That might have helped the parents understanding in a better way which could have led them to rethink their decision. And the life of a child can be saved.

POSSIBLE CONSEQUENCES

In a situation like the case above where it is clearly argued that Parents failed to take an appropriate decision. Dilemma occurs between two principles one is from the side of parents in practicing autonomy and other is from the side of HCP in providing beneficence towards child. If HCP use his professional power and adopt a holistic approach to discourse all the concerned issues and their possible consequences realistically. This may support parents to change their mind and life of a child could be saved. As parents are ethically bound to choose a reasonable alternative that promotes their child wellbeing. However, HCP's may face disagreement, rejection, and ambiguity from the child's family.

RECOMMENDATIONS

HCPs' should adopt a holistic and family-centered approach to the child and its family. Most of the times the matter is only resolved through a change in approach. The trust of parents on the health care team that they all are following the principle of beneficence towards their child will help in changing their minds [10]. The more focus should be on the medical curricula to improve the communication and counseling skills towards patients that guide them in life-threatening conditions. Training

workshops should be conducted to improve health care professionals' communication. A multidisciplinary approach should be adopted in dealing with parents having children with serious illness to address all aspects of physical, mental and psychological issues. There is a need to developed policies to deal with such an ethical dilemma and these policies should guide if there is a risk that parents' autonomy might put the child's health in danger [11].

CONCLUSION

In the hospital, the psychological and emotional stress due to chronic and life-threatening illnesses of children greatly influences the coping skills and decision-making capacity of parents. Together all these factors result in parent's hostility towards selecting treatment options. HCPs continuously deal with such cases. When HCPs' are more expert in communication and counseling skills parents offer to revert their decision.

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