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'AOR' discharge in Paediatrics – An Ethical Conundrum

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ABSTRACT

At own risk discharge (AOR) in the paediatric setting is a complex phenomenon due to the triad of patient, caregiver, and clinician's involvement. It would cross disciplines from legal (child protection), moral (professional conducts and legal decisions), and ethical (age, condition, and nationality) in managing these situations. There are certain ethically acceptable practices that can be approached in the decision making process such as respecting autonomy, individual's competence, the truth, patient's confidentiality and avoidance of paternalism, and all conflicts of interest. We should aim for a collaborative effort in decision making to prevent AOR. Here, we illustrate a case where parent opted for AOR to seek for alternative medical treatment. The article discusses the ethical dilemma when dealing with potentially life-saving conditions.

Keywords: *at own risk, discharge against medical advice, leave against medical advice, paediatrics, child protection, neglect, ethics, moral, Gillick competence, child act*

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INTRODUCTION

AOR is an acronym for 'at own risk' or in the current literature, leave or discharge against medical advice (LAMA/DAMA). It is an act that causes an irreversible breakdown in the patient-clinician therapeutic relationship, resulting in the discontinuation of the physician's duty of care and professional liability for patient care. According to studies, there appears to be an increase in AOR action over the last decade (1). Children are more vulnerable to such discharges because they are less involved in the decision making process (2). The prevalence of leaving against medical advice varies between countries and healthcare facilities, with percentages ranging from 1.2% to 31.7% (3). It is

more common in patients with serious, terminal illnesses or with unclear treatment benefits. In the paediatric population, it deals with multiple issues related to decision making, appropriateness of parental request, socio-economic factors, possible neglect through denial of medical care, and potential harm related to such actions. The current focus on decision making in the context of patient's relationship with health care providers is more towards collective and shared decision. Absolute paternalism or consumerism are no longer accepted as regular practices. This is to allow parental understanding on such issue without any emotive influences. We illustrate a case of parental AOR following their child's diagnosis of acute leukaemia.

CASE

A one and half year-old boy presented with prolonged fever and generally unwellness. He was noted to have hepatosplenomegaly and blood investigations showed features of pancytopenia suggestive of acute lymphoblastic leukaemia. In order to confirm the diagnosis, a bone marrow aspiration was done. He was in the ward for a week before the results were formalised. There was a continuous communication with the parents, informing them of all possible scenarios during the child's admission to the ward. Unfortunately, the parents requested an 'AOR' discharge in order to seek alternative therapy.

There are a few issues related to this case:

Can we consider parental decision as valid if the decision goes against the medical advice such as in AOR?

What are the ethical issues in AOR? Is the action considered as neglect of care in the Malaysian context?

DISCUSSION

Within the authors' institution, a flowchart, shown in figure 1, was agreed upon by all stakeholders potentially involved in dealing with AOR decisions made by parents in two distinct situations.:

(1) patients who have a good prognosis while undergoing treatment, but a poor prognosis when allowed home against medical advice and (2) patients with a poor prognosis, even if the hospital-based care is maintained.

Examples of (1) would include a child with severe neonatal jaundice requiring intensive phototherapy; infants with meningitis requiring intravenous antibiotics; infants who are recovering from conditions that impair their ability to take oral fluids; and a variety of other similar situations. In such cases, ethical and legal implications of AOR are obvious. Under the Malaysian Child Protection Act, parents do not have the right to deny their children such lifesaving or disability preventing treatments. The flow chart was designed to assist doctors who want to protect these basic rights to care for children in achieving a smooth implementation of what is stated in the Child Protection Act. It involves an active involvement of medical social workers and child protectors.

Examples of (2) would include palliative care patients who may benefit from ongoing hospitalisation. In such conditions, caregivers are encouraged to collaborate with parents to find the best solutions, enlisting the help of home care teams from government or non-government organisations..

The case discussed above does not fit into either of these categories and requires special consideration from health care workers. The prognosis of ALL in children is not excellent, but with adequate therapy, a long-term survival rate of about 80% or higher is possible. Some of the mortalities are not caused by the disease itself, but by severe drug side effects.

It would feel unethical and morally wrong to allow parents to deprive the affected child of this good chance of cure, just as it would feel unethical and morally wrong to apply the Child Protection Act in the way that it is applied for the patients discussed above in category (1).

The following important ethical and communication principles/ideas could be considered:

We want to respect the parents' beliefs and convictions as much as possible, but we also want the child to have a good chance of healing through intensive chemotherapy. Could it be possible/acceptable to let the child receive both forms of therapy simultaneously? One of the authors recalls traditional healers visiting the ward after all necessary infection control precautions had been agreed upon, saying their special prayers, and carrying out some of their rituals there. The child continued to receive essential medical care while recovering completely from the disease. In this situation, it was expected that the parents would attribute the cure to traditional medicine rather than medical care, but this was a setback that medical practitioners accepted because the child's best interests were still served.

Upon receiving the bad news, the parents go through the grieving process. The first stage is denial, which is followed by anger, negotiation, and sometimes other stages before arriving at acceptance. Keeping this in mind, psychological support and counselling may be beneficial in shortening the grieving process. When parents fully accept their child's condition, their resistance to proper medical care may reduce. The ethical issue is that postponing therapy for a child with ALL, while the parents go through a long grief process, may significantly reduce the chances of cure.

Within the rural areas of Malaysia, the family unit is still very powerful. Patients may be reluctant or have difficulty persuading their most respected family members of their needs for treatment. Some of our adult oncologists prefer to break the bad news in front of several family members, including the most powerful opinion leaders and decision makers. While this approach may not be in accordance with the patient's right to confidentiality, it may make it much easier for the patient who wants the therapy but is having difficulty convincing his family members on his own.

Cultural influences and extreme beliefs may be strong in certain child caregivers. Doctors may be not the best person to deal with such issues. In certain situations, the involvement of religious experts or other people who are not directly involved in hospital care may be helpful.

Financial constraints may play a determining role in parental refusal of therapy. It is essential that medical caregivers probe into the reasons for refusal of essential health care and offer patients and their parents assistance in resolving the issues that have arisen. Some people may benefit from referrals to appropriate NGOs, while others may benefit from parent support groups.

Paediatricians, as healthcare professionals, play crucial roles in the protection of children, either directly or indirectly. Children are vulnerable because they lack the ability to make informed, balanced, and free decisions based on the information provided. Although this is not always the case, children's decision making autonomy is usually carried out by their parents or caregivers because they lack adequate understanding of such processes. According to the Malaysia's Age of Majority Act of 1971, any child under the age of 18 is regarded as a minor, and parental consent is required in most situations (4). The consent age, which is 18 years and older, is therefore the basis for maturity and

sound decision making. In Malaysia, Gillick competence (competence of children under the age of 16) could not be considered. Gillick competence describes whether a child (under 16 years of age) can consent to their own medical treatment if they have enough intelligence and maturity to understand the nature and consequences of treatment (5).

Parents are more qualified than most to decide what is best for their child because they are aware of their child's unique needs. This decision is typically made out of love and care rather than selfishness or negligence. Parents' judgement may be influenced by a variety of factors, including medical deterioration, self-reliance, child suffering, family pressure and circumstances, burden of care, financial constraints, hopelessness related to the disease state, reliance on traditional treatment, parents' limited medical knowledge, quality of life, and doubt or mistrust of doctors (2,6). After receiving the bad news, the parent would be grieving and could intentionally or unintentionally make a careless decision. The healthcare professionals, on the other hand, might feel pressured to treat the patient as best they can while also feeling worried and concerned for them. Parents or even patients would insist on being discharged despite having access to sufficient information regarding the effects of AOR. Adult patients should be allowed to leave the hospital at their own discretion. However, for paediatric patients, several issues must be considered particularly the child's overall wellbeing.

Both parties (parents and healthcare providers) must agree on a common goal of care. Since the capacity is difficult to predict and best interests are a factor, a more humanistic and morally sound approach is required. The main source of concern would always be abandonment and neglect in the care. Neglect is complex and subjective due to a variety of factors. It is the failure to provide the necessities required for children's development, which include health, psychological, nutrition, learning, shelter, and a safe living condition (7). Literature touches on factors such as persistent failure of care, cultural appropriateness, motives, likelihood of harm, and developmental necessities. In our case, the action of AOR may harm the child as a result of parental actions or inactions. It is important to document the discussion, negotiation and deliberation process, and the decision should be based on balanced viewpoints, giving weight to the needs and desires of the family (6). In essence, providing a family-centered care through measures like using the health care facility's informational and motivational support resources as well as understanding the patient's family dynamic, will assist in achieving an ethically sound resolution (2).

Paediatric AOR requests are best managed when clinicians ensure that the patient's best interests are met, understand, and act on their professional obligation, and engage in guided discussion with patients and families. This should be based on the standardized process and shared decision making (8). While parents have full authority over their kids, it's important to recognise that despite their insistence on AOR, especially for kids with good prognoses, they cannot deny their kids a specific treatment based on standard care. One of the key issues here is communication. Previous study has found that dissatisfaction with physicians and hospital staff, family disturbance due to the presence of other children at home, an inadequate economic situation, and being away from home could all influence parental critical decisions (9). These issues must be addressed in accordance with a standard communication skills interaction and clinicians must ensure that actions are taken in the best interests of the child. Additionally, it is important for the health care providers to emphasise that their opinion is probably objective and broader in the sense that other specialists would have been consulted and came to a recommendation based on several factors.

Discharge policy should be made to assist borderline AOR cases. The premise for using AOR guideline is to prevent neglect of care and supervision by the parents. Even when the prognosis for the disease is unclear, it is important to abide by the available guidelines in cases that are on the borderline and uncertain as to whether neglect should be labelled or not. The fear among health care professionals and medical social workers when counselling the parents is the stigmatization of labelling parental act as maltreatment. The cultural context is also important, such as the assumption

that neglect of care occurs due to the lack of standard medical approach. Parents may argue that their roles as parents are not diminished even if they showed conscience using traditional or alternative medicine approach as in the reported case. This alternative therapy has given patients an option in their medical care – such as receiving it at home, which could be comforting while at the same time preventing the child from going through painful and difficult procedures (9). Despite being an alternative treatment, especially for a condition that can be cured, this is not regarded as evidence-based standard care.

Informative observations on child maltreatment in relation to health care provision amongst parents/guardians in some healthcare providers revealed a lack of awareness in this matter. Parents generally feel that they have rights over their children and have overlooked the child's own right and need for protection. They are seldom aware of the law that existed to protect the children. Amongst the healthcare providers, uncertainty of the law and the avoidance of litigation sometimes blurred the interest of speaking for the children. As health care providers, it is imperative to clearly identify the moral issues involved, and this form of analysis takes the evaluation of one's instincts to reveal the speculation, values, and moral beliefs underlying the situation (10). In this case, understanding the type of problem, the appropriate response, and the right thing to do requires an ethical analysis. When we encounter this kind of ethical conundrum, it is ideal to use the procedures already in place to comprehend and lessen the restrictions on acting ethically. Unfortunately, our resource shortage has not improved. The limited psycho-social support, financial aid, and palliative care within the community makes it even harder and more complicated to resolve the AOR discharge issue. Educating all parties on the rights of the children and the responsibilities to protect them would be an urgent action.

In order to resolve the issue, it is crucial that medical professionals possess knowledge of children's rights and safeguarding procedures and exhibit sound clinical professionalism (Figure 1). The approach for this would include improved communications between doctors and the caregivers to avoid potential conflict. Information sharing must be consistent; even with a slightly worse prognosis, it is better for the child to receive care than none at all. Documentation of the reasons why parents make such decision is essential to avoid care litigation. Medical social workers should be able to offer additional psychosocial care in the event that negotiations fail and support the parent in making decisions. Collective decision making between social worker and the managing physician is essential prior to the activation of child act. AOR could be allowed if the child's medical condition allows for home survival with acceptable health status, but this must be done with discharge planning, follow-up, and in coordination with a child protector (3). The Child Act has stipulated that it is illegal for parents to remove their child from a hospital against medical advice (AOR), and individual doctors must take appropriate measures to protect and support these children (4).

CONCLUSION

AOR is a highly charged area in which health care professionals' actions must be based on the rights and well-being of children. Clinical problems with significant ethical entanglement pose an increasing dilemma and rarely have as simple solution. If an action is deemed harmful, steps must be taken to protect the child. In a borderline case, consensus can be reached through multidisciplinary consultations, improved communication, and follow-up planning. This workflow may help in reducing the severity, complications, and consequences of AOR. It can also prevent extra hospital expenses.

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