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Case Report

A PATIENT WHO REFUSED MEDICAL ADVICE: THE DOCTOR AND THE PATIENT SHOULD LOOK FOR A COMMON GROUND

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ABSTRACT
Treatment refusal is a common encounter in clinical practice. The process of deciding to refuse treatment is often complex. It is our responsibility to try and understand this process of decision making and the underlying reasons for treatment refusal. Many of these reasons are often rational in the context where the decision is made. The patients could be making the best decision for themselves even if these decisions are not necessarily the best in our mind. We should at all times discuss our treatment options and assess their ability to make decisions in achieving common goals. These goals should balance our best treatment strategies and the patients' best interest. This article discusses the reasons underlying treatment refusal and how we can achieve a common goal with our patients.
Key words: *Against medical advice, decision making*
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INTRODUCTION

Patient's decision to discharge "at own risk" (AOR) is a common event that health care providers will face in their practice. AOR, an unofficial term used in Malaysia is cited formally as 'against medical advice' in the world literature. Incidence varies with different centres and clinical settings. It occurs more commonly among illnesses that are more serious, terminal or of unclear treatment benefit. The rate ranges from 6.4% among general hospital patients to 13% among HIV-positive patients.[1,2] There were significantly higher rates of readmission, and longer hospital stay for any readmission.[1,3] Local data on treatment refusal is scanty. We can find only one prospective survey of AOR discharges from Hospital Taiping, giving an incidence of 2.1%.[4] It is important for medical practitioner to be well equipped with the appropriate skills when we face such encounters.

CASE ILLUSTRATION

Mr. WHY, a 61-year-old gentleman presented in August 2004 with complaints of dyspnoea on exertion and orthopnoea for one week. Apparently he had reduced effort tolerance for the last thirty years. He was told to have a "slit" in the heart two years ago when he presented to a cardiology centre. He was offered an intervention but he refused. He remained well and was able to work until recently when his symptoms affected his daily activities. The diuretic he was taking improved his dyspnoea to some extent. There was cardiomegaly and a grade 3 pan-systolic murmur over the aortic area. Clinically he was having heart failure and was admitted for a complete cardiac assessment. His echocardiography confirmed an enlarged heart and presence of sinus of valsalva rupture, causing a left to right shunt from aortic root to right ventricle. There were functional mitral and tricuspid regurgitations. The ejection fraction was only 34%. A final diagnosis of sinus of valsalva rupture with congestive heart failure NYHA functional class IV was made. He was counselled on the need for surgery, but he refused any surgical intervention and insisted on conservative management. His condition improved and stabilised to functional class II after a five-day stay in the ward. As he was not interested in pursuing surgical intervention, he was subsequently referred back to the primary care clinic for conservative management and follow-up.

During the subsequent follow-ups in our primary care clinic, we managed to explore his understanding and concerns about the proposed cardiac surgery. He was told about the need to have two-stage procedure to rectify his heart lesion with a total cost of RM65,000. He anticipated that he would undergo cardiac rehabilitation which might take another month or even longer. Not unexpectedly, he was not guaranteed of a good outcome from the surgery. As the sole bread-winner in his family with five children, he already had difficulty keeping his ends met. He was only paid daily for his work as a mechanic. Any absence from work meant no income for the day. He could not imagine he could provide enough for his family during his hospital stay, let alone the

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need to pay the hospital bills. Furthermore, he had had this heart lesion for the last 30 years and was able to cope with it fairly well. He had a strong belief that he could go on with conservative management (medication) for the next two years and by then, his eldest son would have graduated from school and therefore can help to support the family. He had considered all the alternatives and worked out what was best for himself and his family. On the subsequent follow-ups in the clinic, he had remained stable and was able to continue working.

DISCUSSION

Treatment refusal is a common encounter in clinical practice. It was a challenging situation in managing him when he did not 'listen' to our advice or adhere to our management plan which we thought was best for him. We had to keep a check on our anger or frustration at all times so as not to jeopardise our relationship with him. Should we continue to persuade him or even coerced him into adhering to our management plan? What if our best management plan turns out to cause him more harm? Should we fall back on patient autonomy and let him decide what is best? We hope to discuss some of these ethical issues below.

Our role as health care providers

Needless to say, it is most inappropriate for us to dismiss patients who refuse treatment without further assessment of the underlying problems.[5] The extreme of medical paternalism (the treating doctors assume the role of sole decision maker) or absolute patient autonomy (where patients are given absolute power in decision making) are both inappropriate. A balance must exist between these two models to allow negotiation and shared decision making,[6] particularly when the treatment benefit is less clear. Even in developing countries where patients may expect a more paternalistic kind of medical care,[7] we have the duty to convince them to accept our treatment plan after considering the patients' best interests.[8] In the event of treatment refusal, we must always make an attempt to assess the patients' ability in making such a decision and to find out the reasons for treatment refusal.[9] It does not matter so much about their decision but rather how the decision is made.[10,11] Only by these can we be assured of better understanding of why they behave in such a way and not assume that they do not trust us. We also need to ensure that the correct information is given to them as to what we can offer, in language that is simple enough for them to understand. We should counter-check what they have understood as they often misinterpret what is said during difficult situations of decision making. Unless we go through these processes, we cannot claim we have exercised patient autonomy in decision making because the pre-requisite to this is that they must be well informed on the benefits and harm of the treatment options.[8] In short, we must at all times act in the best interest of the patient as much as possible and keep our doors open to our patients if they are to return to us for further care.

Ability to make a decision

At times, we are quick to judge the patients as irrational when they act against our treatment plan. We should not make this assumption unless we have assessed how they have come to this decision and their ability to make sound decisions. Making the assumption that they are either competent or incompetent in decision making will not bring justice to them. If we assume that they are competent, we are risking those who may be incompetent and lessen our societal role in providing protection for them.[9] We have an obligation to protect our patients from potential harm caused by not agreeing to our treatment. On the other hand, if we assume they are incompetent, we are acting against the best interest of the patients who may be competent in decision making.[9] One way to find out whether they are competent enough in decision making is by communicating with them and assessing their process of decision making. We need to find out whether they fully comprehend the benefits and harms of our treatment plan and appreciate how these facts apply to their situation. Are they able to reason out their decision logically by taking into consideration their social lives and cultural beliefs? Are they able to express a choice and consider the pros and cons of other alternatives? If patients are able to demonstrate a good, logical and rational decision making process, there is good reason to take patients' opinions seriously and reconsider our treatment strategies to balance patients' needs with our treatment objectives. Conversely, if the decision making process is illogical, we have the responsibility to assess the risk involved if patients' wishes are followed. We may want to give in if the health risk is minimal. However, if the potential harm is substantial, then we need to find some other means of persuading patients to follow our treatment suggestions. These may involve giving patients some time to assimilate the information, counselling or even getting help from someone the patients trust most.[9] These are not easy tasks unless we have the genuine interest to act for the benefit of our patient.

Reasons for going against medical advice

People do not usually go against medical advice if the advice is of good intention. When patients risk going against medical advice, it signals some underlying problems[12] unless the patients do not possess a sound decision making capacity. We have to look at these problems from multiple perspectives; factors related to the patients or family, factors related to the physician as well as social and organisational issues.

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Patient or family factors

Besides patients being incompetent in decision making, poor understanding or misunderstanding could be the main problem. When patients are in a stressful situation, information received may differ substantially from its original meaning. Partly it could be due to denial of the truly bad situation, poor registration of bad news or even confusion by multiple sources of information. This distorted information in their mind would result in unwise decision making.[12] From the social, cultural and religious stand, patients may have very different values of what is the best for themselves.[13] They may have different goals and agendas. Some prefer good quality of life as opposed to longevity in palliative care. Some emphasise on the welfare of other family members rather than their own health as they have a strong sense of responsibility to the family. Some give higher priority to their parents' opinion as it is taboo to disobey parental instruction. Some believe in fate and that all happenings are god's will. With differences in priorities in life, the decision made will certainly be different if we do not share a common goal. Fear of therapy could also be another reason. This is particularly so if the patients had gone through similar bad experiences by themselves.[14] For example, a painful bronchoscopy experience may deter a patient from accepting the same procedure again. Above all these, we need to keep in mind the possibility of secondary gain by the patients.[12] Some patients may refuse further rehabilitation in order to remain sick and receive further compensation from certain agencies.

Physician related factors

Sometimes, it is uncomfortable for us to take a passive role in patient management thus we view this as a medical failure.[12] We face the dilemma of deciding on the best treatment plan when our treatment only confers marginal benefit. This happens when we face uncertainty in prognostication. This can drive us to act against patients' wishes. We must not view 'no active intervention' as medical failure but rather take into consideration the overall benefit to patients. What the patients want might just be expectant management or continuous support. Hence, balancing the psychological need and social and physical health is of paramount importance. It is easy for us to underestimate their quality of life. We may think that they are worse off without treatment, but to them, proceeding without treatment might be the best choice. We should keep away from the temptation to decide what is best for them; rather we should discuss with them what would be the best. This can minimise the chances of patients going against our advice. As with our patient, undergoing surgery may not be the best option for him although traditionally we think that sinus valsalva rupture has to be repaired surgically and yet we are uncertain of the prognosis in him who has NYHA class IV failure.

When doctors are over-worked, stressed and frustrated, it is less likely for the doctors to spend time discussing and providing optimum information.[14] Patients are lay people who need time to digest a load of medical information. There is also the possibility that we doctors might not be motivated enough to spend time with patients and are not interested to hear more about patients' psychosocial problems.[12] Lack of knowledge of other treatment options may also contribute to why patients refuse our treatment plan. They may know of other alternative strategies which, in their opinion, are better. If we are well aware of these alternatives, we are better able to discuss the benefits and harms of each strategy with them. These will obviously increase their confidence in us and the chances to accept our treatment advice. More importantly, the physician-patient relationship is the main factor contributing to majority of the cases of treatment refusal.[15] Good physician-patient relationship allows a trusting relationship to develop. Most patients will rationally agree to doctors' treatment strategies if better communication is established and patients are kept fully informed by their doctors.[16]

Social and economic factors

For many patients, health is just one of many priorities in their lives. With the escalating healthcare cost, the budget they can allocate for their healthcare can be limited. Their emphasis is heavily influenced by their own sets of values and psychosocial issues. If health care costs can be made more affordable and financial aid made more accessible to patients, they might opt to take our advice. Patients often felt frustrated when they apply for social welfare assistance.[17] Mr. WHY was referred to social welfare department for financial assistance but because of his previous negative experiences, he turned down the referral. Apparently he was questioned at great length about his social life and he had to visit the social welfare department many times and yet was not successful in obtaining any financial aid.

Achieving common goals with our patients

We try to estimate what the best option for our patients would be. What we could be doing most is just having the best guess of the best option. Our suggestions are truly from our perspectives as the treating physician. These are often the best options from our patients' point of view. However, there would be situations where what we suggest contradicts with patients' wishes. Patients often do not reveal their wishes if they are going to be different from their doctors. Only through tactful and patient-centred approach might we be able to elicit patients' ideas, concerns and expectations. Coupled with good communication skills, information sharing, truthfulness and genuine good intentions for the benefit of patients, we can achieve common goals. These common goals may not be the best in our mind but could be the best for our patients. This process takes time and sometimes

stretches our patience but it is well worth the effort in order to avoid injustice to our patients.

It is hard to comment on exactly what has happened between Mr. WHY and his attending physicians. After long discussions on the issue, we can confidently conclude that his main reason for treatment refusal was financial constraint and his unwillingness to received financial aid. In his opinion, getting financial aid involved too many procedures and too much time. With uncertainty of the prognosis and treatment outcome, he chose to continue going on medication instead of undergoing surgery. He was rational in making his decision and was clearly aware of his problem as evidenced by the fact that he had kept to his follow up appointments and showed much concern for his problems.

CONCLUSION

Patients who go against medical advice should not be viewed as uncooperative patients. Health care providers should strive to understand the underlying problems leading to the treatment refusal. The causes include problems with decision making (inability to make rational decision) and genuine reasons for accepting the medical advice. Much conflict can be avoided if these underlying factors are explored. A concerted attempt to search for common ground is more likely to result in acceptable compromise between the doctor and patient.

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Anti-obesity drugs modestly reduce weight but have specific adverse effects

Rucker D, Padwal R, Li SK, *et al*. Long term pharmacotherapy for obesity and overweight: updated meta-analysis. *BMJ*. 2007; 335(7631):1194-9

This is a meta-analysis of 30 randomised controlled trials of approved anti-obesity drugs used in adults for one year or longer. Compared with placebo, orlistat reduced weight by 2.9 kg (95% CI 2.5-3.2 kg), sibutramine by 4.2 kg (95% CI 3.6-4.7 kg), and rimonabant by 4.7 kg (95% CI 4.1-5.3 kg). About 30-40% of patients were lost to follow-up. Notable adverse effects are: gastrointestinal symptoms (orlistat), lowered HDL-C (orlistat, sibutramine), increased mood disorders (rimonabant).