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Perspective Chapter: Who Is Making Decisions? An Open Letter to Healthcare Professionals in the Developing World

Rasheed Ofosu-Poku

Abstract

The educational standard of people living in low- and middle-income countries (LMICs) such as Ghana is relatively low. Thus, most resources of information about health available on electronic and print media remain to a large extent non-beneficial to them. They rely mostly on healthcare professionals to discuss about their health, illnesses, resources available for care, and how and to what extent the available resources can meet their needs and expectations. Some healthcare professionals in these LMICs, instead of taking the opportunity to carry out these educational and empowering discussions with patients and their families, assume a paternalistic role, making decisions unilaterally and involving them only minimally in providing care. This article, instead of being written as a scholarly referenced paper exploring ethical issues of autonomy and informed decision making, has been worded as a letter to healthcare professionals. Although it addresses healthcare professional in LMICs in general, it does not in any way imply that none adheres to these important ethical principles.

Keywords: healthcare professionals, informed decision making, autonomy, paternalistic, patients and family

1. Introduction

The educational standard of people living in low- and middle-income countries is very low, with one-third of its youth dropping-out of school before secondary level of education [1]. The literacy level among graduates of tertiary educational institutions in most low- and middle-income countries is also low [2]. On account of this poor literacy rate, majority of people living in these countries depend on healthcare professionals for information about health and illness [3]. A similar situation exists in Ghana, a lower middle-income country.

The burden of chronic non-communicable diseases in Ghana is rising [4], and the importance of patients and their families understanding the disease they are suffering from, the treatment modalities available, and the objective of each modality is crucial to adherence to therapy [5–7]. However, in the course of caring for patients in the last few months to a year of life, the author has noted a generally poor level of knowledge among patients and families about the disease affecting

them and the objective of therapy they have sometimes received for several months. They, therefore, present to the palliative care unit with expectations of cure and expressions of feeling of anger at and disappointment with healthcare professionals for not being open to and honest with them from the beginning.

This article has therefore been addressed to colleague health professionals as a letter, to highlight the voices and cries of these patients and their families, and to appeal to healthcare professionals to involve them actively rather than passively in their care.

2. The letter

My dear colleagues,

I would like to congratulate all of you – doctors, nurses, pharmacists, laboratory scientists, health information officers and other healthcare professionals in the world in general and developing countries in particular – for the tremendous work you do every day and the sacrifices you make for your patients.

We, however, do not have to let the feeling and thought of having done or sacrificed a lot cause us to relent on our efforts. We cannot rest until our patients and their families are satisfied with the care we provide. How can we get them satisfied and grateful for the care we render?

How can patients and their families be satisfied and grateful for what we do if they do not understand their illness, our plan of management, and the role they have to play towards care? Thus, our goal – patient and family satisfaction – seems an impossible feat without discussing with them what we think is happening, the services available to meet their healthcare needs, and the possible consequences each course of action chosen may result in.

My dear colleagues, patients and their families are not oblivious of what is happening to and around them. They know the signs and symptoms they present with better than us. Our specialty is in our ability to connect the different issues they present with to make meaning – to arrive at a diagnosis. When they present to us, they seek first to understand what exactly is happening to them; then what we can offer and how what is being offered will help them.

Unfortunately, on both counts, health professionals in low- and middle-income countries such as Ghana generally perform below expectation. How much do we discuss with patients and their families to help them understand what they are experiencing? Most of the time, we say nothing after hearing their issues and asking a number of questions; we just hand over a prescription and/or laboratory request. Few times, especially when the patient has a life-limiting illness and wishes to understand what is happening to them, we tell them half-truths under the guise of ‘protecting them’ or ‘maintaining their hope’. Really? Are we protecting them or protecting ourselves? Do we not fear admitting that we do not have all the answers, and that we cannot offer cure?

Does the course of a life-limiting disease change by keeping information away from the patient and/or family? Does it change the fact that our medical or surgical therapy may not offer cure but reduce the disease burden, if anything at all? If our answers to the above are the obvious ‘no’, then are we not putting the patient and family at a great disadvantage of not putting right their affairs before the disease causes them to be incapacitated?

For a second, let’s turn around the table. Ask yourself, ‘if I or my relative is suffering from a life-limiting illness, will I want to be told everything so that I am mentally prepared?’ For most of us, our answer will be in the affirmative. That information is so valuable, not only in preparing oneself mentally or emotionally

towards the imminence of the inevitable, but is the basis for pulling together all physical, social and spiritual resources one can have to cope with the stresses associated with suffering a life-limiting illness. So why keep from patients such valuable information about themselves?

Consider the case of a mechanic who is called upon to attend to a faulty vehicle. After asking a few questions from the driver and checking a few issues on the vehicle, he scribbles a few things on a sheet of paper, directs that whatever is stated thereon be obtained from a particular shop to get the vehicle fixed, and takes his leave. Who can stand that? That is why the mechanic does not even imagine such a situation. Rather, what he does is to explain to and show the driver what he thinks is wrong, what he can do about it, what is unavailable and has to be purchased, where to purchase it, and the options available to resolve the fault so that the driver will make a choice – an informed choice, an informed decision. So why is this logical principle so challenging for most healthcare professionals?

The argument of ‘the patient/family must ask if they have any questions’ is feeble. Over the course of time, we (health professionals) have succeeded in creating around us an aura of being ‘superhuman’ rather ‘gods’. We have successfully replaced respect for the profession with fear of the professionals. Thus, our patients and family cannot even ask us what we think about their illness. The result is that they will go to those who will provide them information about the illness to help them make meaning of the situation. As to whether that information is true or false is really a secondary matter to them. One would be surprised to learn how much patients and their families pay for seeking such care that only causes their health to get worse. In the end, they report to the hospital with the patient in a worse state after exhausting all their resources. Interestingly, our reaction as healthcare professionals is to blame them for not reporting to the hospital at the outset. What we fail to recognize is that we are primarily responsible for their course of action. The earlier we as healthcare professionals begin to look within ourselves – our attitudes and actions – to identify our role in improving the image of our professions and the healthcare system, the better it will be for ourselves and the people we have pledged to serve.

Another intriguing related issue is how healthcare decisions are made in a system where patients and family have little information. Do clinicians just make unilateral decisions for patients and their families? If no, on the basis of what information do they contribute to decision making about their care or the care of their loved ones? Only two logical conclusions come to mind, either clinicians really make decisions unilaterally for patients and their families, or they provide some information and impose their decisions. In both cases, such clinicians occupy the role of ‘fathers’ to the patient and family. That is, they convey to patients and their families through actions the following message: *“we are more knowledgeable and experienced than you in caring for the sick. We want to do ‘A’ and ‘B’ for you or your relative. Just do it and ask no questions because you, like a child, have no knowledge and experience in healthcare”*.

That is exactly how patients and their families feel. Hence, they ask no questions. When they get fed up with prescriptions and laboratory requests for which they see no direct benefit to the wellbeing and quality of life of the patient, they request discharge. No amount of words can change that decision because they have gone through such an awful experience with healthcare professionals that, they would rather stay home and die in peace. That is their reaction; they are not involved actively in any decision making, but when they make the only decision about their care that has actually come from them, we try to talk them out. That will not work.

O my dear colleagues, where is the ethical principle of autonomy we learnt during our training? Why have we regulated informed decision making to the background and harnessed for ourselves a paternalistic role in rendering care in the 21st century.

O my dear colleagues, let us keep in mind that patients have the right to every information about themselves and their care. They have the right to seek another opinion from any other person they desire even if we disagree with their choice. Our responsibility is to provide them all the information they need to make whatever decision is right to them, and to provide them the best care we can offer in the context of their decision. There should be no coercion or imposition of decision.

If we really desire the best for our patients and their families, we must completely deflate our pride and come down to their level, offer them every information they need to know regarding their illness and the care we are providing, involve them actively in decision making at every step of treatment, and respect their decisions even if we are uncomfortable with it. If this simple but golden principle is kept in view, the public perception about healthcare professionals practicing allopathic medicine will totally transform and we will in no time be their first and only choice in seeking healthcare.

Yours sincerely,

Rasheed Ofosu-Poku.

The author is a nurse specialist in palliative care at the Komfo Anokye Teaching Hospital in Ghana. Palliative care services in Ghana are available in isolated facilities in Kumasi (Komfo Anokye Teaching Hospital), Accra (Korle-Bu Teaching Hospital) and the Eastern Region (Tetteh Quarshie Memorial Hospital). With respect to human resource, the number of trained clinicians providing palliative care services is inadequate to meet the need of the hospitals and the administrative regions within which they are found. Thus, many patients who need palliative care never get the chance to receive it. Furthermore, most patients and families who eventually get referred for palliative care live for a few more weeks to few months, and are thus unable to obtain all the benefits associated with palliative care services. The lack of a national policy on integration of palliative care within Ghana's healthcare system is, perhaps, the greatest contributory to the inadequate availability of palliative care services in the country.

The availability of essential drugs such as opioids is crucial to the practice of palliative care. In Ghana, morphine is increasingly being made available as a prescription-only drug in pharmacies in its major cities. However, other essential opioids such as methadone are completely unavailable for use in palliative care. Thus, pain management is less than optimal in patients with severe renal impairment and those with bone metastases whose pain is difficult to control with other opioids. Fentanyl transdermal patch is available in only few pharmacies in the two major cities of Accra and Kumasi.

Thus, although some effort is being made in Ghana to provide palliative care services, there are many challenges ranging from lack of a national policy on palliative care to poor human resource capacity and poor availability of opioids for pain control.

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Conflict of interest

The author declares no conflict of interest with respect to this article or its publication.

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