

RESPECT FOR PATIENT AUTONOMY: A PATIENT PERSPECTIVE

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Summary

There appears to be dissatisfaction by patients in Ghana with the way their doctors communicate with them. The perception is that doctors fail to respect their autonomy by failing to adequately inform them of their health condition and also fail to involve them in their health care decisions. Patients want doctors to use their medical training to promote a partnership in the doctor-patient relationship where the doctor uses his or her superior knowledge and skill in medicine to

acknowledge, encourage and support the patient's right to self-determination in his or her health care. If doctors did that, patients will be more satisfied, the doctor-patient relationship will be enriched, trust between the doctor and his patient will be enhanced and patient care will also be enhanced. Although there may be difficulties for doctors to adopt this approach, those difficulties are not insurmountable

Key words: *Autonomy, Patient autonomy, Self-determination, Doctor-patient relationship, paternalism*

Introduction:

The last few decades has seen an increased emphasis on respect for 'human rights' in many countries in the world. This has led to changing attitudes and expectations in society. Individuals in society increasingly expect their human rights to be respected in every walk of life, including in their health care. In health care respect for human rights translates into respect for patient autonomy. Respect for patient autonomy has been interpreted to mean a number of different things in different circumstances. However the ways that patients universally appear to want their autonomy respected are; to be listened to, be provided with information about their health condition, and be involved in the management decisions about their health care^{1,2,3}. A number of studies conducted in Ghana have shown these expectations to be true of Ghanaian patients^{1, 4, 5, 6}. Respect for patient autonomy, which is believed by some to be the most important⁷ of the four principles of modern medical ethics is also a major determinant of patient satisfaction in health care which in turn is a measure of the quality of health care delivered^{1, 8,9,10}. This means that if doctors are to provide a good quality of care, they not only have to cure their patients' diseases and illnesses, they have to do so by respecting their patients' autonomy, and their patients have to feel satisfied with the care provided. It follows from the above, that if patients are to be able to participate in any meaningful way in their health care decisions, they need doctors to provide them with the

relevant information to enable them do so.

Many doctors in Ghana, as part of their desire to provide a high quality service and in accordance with the requirement of the code of ethics and the patient charter of the Ghana health service, put in a lot of effort to provide information to their patients about their health condition and management, and wish they could do more. However every now and again some patients feel that such information is not forthcoming from doctors, and this makes them feel their autonomy is not respected by their doctors.

The scale of the problem

Recently I came across a Ghanaian online health care blog while searching the Internet, in which I read a story of a woman and her mother's disappointment at the interaction between her mother and the doctor when she accompanied her mother to a doctor's appointment in Ghana¹¹. She was disappointed because she thought the interaction was so brief, the doctor did not explain her mother's condition to her, nor give much thought to her mother's thoughts, ideas, concerns or expectations.

In another Ghanaian online health care blog¹² the recurrent theme was that doctors in Ghana generally fail to inform patients of their health condition when patients consult them. What appears to frustrate these patients the most is the fact that doctors refuse to provide them with information even when they make direct requests for it. Here are just two quotations from this blog;

'... why is it so difficult for doctors to tell their patients what is wrong with them and what they are doing to cure them? Why the silence, the sarcasm or even insults when a patient wants to know what you have found after asking all those 'weird' questions and probing and prodding him/her in all sorts of private places?'

'The arrogance and condescension is sometimes absolutely unbelievable'.

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There was a sense in the communications in this blog that many patients feel offended by doctors' attitudes and practices in Ghana in this regard and certainly feel that their autonomy is not respected by doctors.

Reading these blogs brought back memories of an experience that my father and my siblings had not too long ago when my father was admitted to a hospital in Ghana with a very serious illness. The medical care from the doctors and nurses was excellent but my father and the rest of the family had serious concerns about the flow of information from the doctors about his condition and progress.

I believe the majority of doctors in Ghana work very hard and do a very good job. I also know that these blogs do not provide opinions in a scientific manner and one cannot draw scientific conclusions from them. I also believe that if I search hard enough I may find a blog containing praises about the good work that Ghanaian doctors do with communication with their patients. However much I like to think that the views expressed on these blogs are that of a few disgruntled patients, and my family's experience is the exception rather than the norm, if indeed the views are in any way shape or form representative of the views of the Ghanaian society, then doctors have a lot of work to do about the way they relate to patients and the ethics of their practice.

My little experiment

Against the background of what I had read in the online blogs on respect for patient autonomy and patient satisfaction, I decided to do a little study. I had a conversation with a patient within the community that I work in Saskatchewan, Canada, on the subject of 'respect for patient autonomy'. My aim was to find out what her experience with doctors within our community had been when she had consulted them, what her expectations were, and also what she thought most patients expect from their doctors in the doctor-patient consultation. With her views in mind I spoke to a patient who had just recovered from a surgical operation in one of the major teaching hospitals in Ghana to find out what her views on her doctor-patient interactions were and whether her experiences were different from her expectations. I also asked her to tell me what she thought most patients in Ghana expect from their doctors when they consult them. The responses from both patients were similar in many ways. They both want doctors to respect their autonomy and they want doctors to do so by communicating with them. Both of them also believed that most patients expect the same from their doctors.

The aim of this article is to raise awareness among doctors in Ghana of some of the ways in which patients want to see respect for their individual autonomy shown in practice by describing the views of the two patients above, together with my own views, of how patients expect the doctor-patient relationship to look

like, and also to provoke a debate on the issue of respect for patient autonomy in Ghana, particularly with respect to doctor-patient communication.

It is my hope that this article will provide a stimulus for reflection by the busy clinician and the clinician in training on his interaction with his patients and lead him or her to make positive changes in the way he cares for his patients.

Although I refer to the views from these two patients as what patients want, I admit that a study involving the collection of views from just two patients who have university education, in a casual conversation, is insufficient to draw up any meaningful scientific conclusions about the views of all patients. However, these views, I believe provide a good insight into how some if not many, patients expect the doctor-patient relationship to look like and how they want the respect of their autonomy to be in their day-to-day interaction with their doctors.

Autonomy

The word Autonomy means 'self-rule' or 'self-governance'. It derives from the two Greek words 'autos' which means 'self' and 'nomos' which means 'rule' or 'governance'¹³. Autonomy was originally used to refer to nations and states with respect to their ability to run their own affairs. Now it is also used to describe persons¹³. A person is autonomous if he or she is able to act intentionally with understanding of the relevant issues without controlling influences¹³.

Philosophically the meaning and scope of autonomy is very wide. It is the case that everybody is influenced in a way by the environment he grows up in and lives in and by his relationships such as his family and friends¹⁴. In this regard everybody is influenced in a way by others and nobody acts independently of the influences around him. It is also the case that nobody has a complete understanding of all the issues that he deals with prior to making decisions¹⁴. As such, complete freedom from coercion or internal limitations and full understanding are ideals that can only be aspired to and not attained. This being the case, nobody is fully autonomous¹⁴. For practical purposes, most people are considered sufficiently autonomous. The laws in many countries require that every adult of a sound mind and adult years be considered sufficiently autonomous and his autonomy respected unless there is a good reason to do otherwise. In effect individuals with sufficient autonomy should be able to live their own lives according to their own idea of what a good life entails. Respect for autonomy flows from a recognition that all persons have unconditional worth, each having the capacity to determine his or her moral destiny. To violate a patient's autonomy amounts to treating him merely as a means to achieve another person's goal without regard to that patient's own goal¹⁵.

In health care, respect for autonomy has to do not only with respect for the individual, but for the decisions

and choices that the individual makes. Just like the individual, a decision or choice is autonomous if it is made with understanding and without controlling influences¹⁶. Patients can only make free choices and decisions if they are properly informed. Properly informing patients about their condition includes telling them the truth even when the prognosis of their condition is bad and also when mistakes are made about their care.

Instead of respect for their autonomy, some patients feel, as has been described above, that doctors are paternalistic in their relationship with them.

Paternalism

Doctors have traditionally practised by the ethics prescribed by the Hippocratic Oath¹⁷. The original Hippocratic Oath requires the doctor to exercise skill for the benefit of his patient without any mention of respect for the patient's right to self-determination. Traditionally, therefore, the practice of medicine has largely been paternalistic. This means that the doctor has the power to and may override his patient's preferences, choices and decisions and justify doing so by appeal to the goal of benefiting his patient or preventing or mitigating harm to his patient¹⁸. The ways in which patient choices and decisions can be overridden include deception, lying, manipulation of information, non-disclosure of information, the use of coercion and force or indeed outright refusal to carry out the patient's wishes¹³.

Paternalistic attitudes and practices by doctors have until recently been accepted as right by society. They are now considered morally wrong¹⁸. Now the number of people who accept the notion that 'the doctor knows best' and that 'the doctor is better able to determine the patient's 'best interest' than the patient himself is dwindling¹⁷. A patient's best interest is believed to be more than just medical^{19, 20}.

Paternalism was tolerated by society because it was thought that the doctor always behaved in a gentlemanly and benevolent manner and it was believed that any dilemmas that he faced in treating his patient he could resolve by relying on his conscience and integrity to act in the patients' interest¹⁷. History has, however, proven that this is not always the case²¹. Unfortunately, the practice of medicine in Ghana just like in many other countries around the world still remains largely paternalistic^{22, 23}.

So what do patients want their doctor do on a day-to-day basis?

Views from the patients

As stated earlier, the patients I interviewed, just like patients of every background, race or culture, want their autonomy respected²⁴. They expect their relationship with their doctors to be a partnership in which the doctor uses his superior knowledge and skill in medicine to acknowledge, encourage and support their right to know about their health condition and be

involved in their health care decisions. How this relationship should look in practice, as they describe it, is consistent with what proponents of the principle of respect for patient autonomy suggest; which is that their doctor would use his or her medical training and expertise which includes an understanding of the diagnosis and the available treatment options to provide information to them, in ways that they understand and involve them in the management of their medical condition²⁵. They expect their doctor to develop an understanding of them as individuals, not as a disease and to show empathy. They want the doctor to listen attentively, to elicit their concerns and calm their fears, answer their questions honestly, inform and educate them about treatment options and demonstrate sensitivity to their individual and cultural diversity. They expect their doctor to adopt an attitude that enables them to query or clarify their understanding of options that are offered to them and to be able to choose against the doctor's recommendation without jeopardising their on-going care. They do not expect the doctor to consider himself or herself as the final arbiter of all-important decisions²⁶.

At the same time, they do not want the doctor to just do whatever the patients request, or fail to reason with or persuade them to change their minds if their choices or decisions are irrational. They also do not want their doctor to say to them 'this is the diagnosis of your condition and these are your treatment options, make a choice because it is your body', and just stand by and let them make a choice without even providing the relevant information to enable them do so. They do not want their doctor to treat them in an individualistic manner, without regard for their family or social support system. Instead they acknowledge that their social support system is important to them and accept that sometimes other members of their family may make decisions on their behalf. In many parts of Ghana^{27, 28} community elders and others make important decisions including health care decisions on behalf of other members, especially women and children. Both patients accepted that a system where 'recognised' members of the community make decisions for other members is not inconsistent with respect for patient autonomy. They cautioned that the doctor should ensure that patients are in agreement with such decisions and look out for signs of oppression of the patients by others and support the patients against such oppression.

They believe that if doctors practised these, the doctor-patient relationship will be enriched, trust between the patient and his or her doctor will be enhanced and patient care and patient satisfaction would also be enhanced. They admitted that there are still many individuals, particularly in developing nations including Ghana who are still not aware of their rights, and point out that a doctor should not take advantage of that.

One of the striking, albeit unsurprising, things that I picked up from the conversations with both patients was a suggestion that many more people in Canada are aware of their individual rights and liberties and also of channels for redress if they feel their autonomy has been disrespected by their doctor, and are more assertive than the case is in Ghana. This may mean that health care organisations in Ghana and those in positions who are capable of establishing patient redress channels need to put in place the necessary channels if they are not already in place and make patients aware of them.

Barriers to respecting patient autonomy

There are undoubtedly problems that affect doctors' ability to respect their patients' autonomy, particularly in developing countries. This was acknowledged by the patients, who hoped that doctors will take steps to minimize these problems. Some of the problems are outlined below.

A doctor may find himself or herself practising in a location where there is a language barrier. Sometimes interpreters cannot be found. Even when there are interpreters, the doctor may find that there is limited vocabulary to explain medical terms to his or her patient in the language that the patient understands²⁹. Doctors are expected to provide the best health care they can with the tools available to them. A doctor who does his or her best for a patient in a difficult circumstance in which the patient's situation makes him or her incapable of making an autonomous choice is not disrespecting his or her patient's autonomy.

Patients may be illiterate. Illiteracy does not mean inability to comprehend. People who cannot read or write may understand things if explanations are given to them in simple terms and with analogies that they understand.

Doctors' often have a very heavy workload²⁹. Allocating time to explain things to patients and giving patients the opportunity to ask questions may be considered time consuming and problematic. The patients pointed out that doctors need to accept that providing information to patients is just as important as taking a history, examining the patient, making a diagnosis and prescribing treatment. If this is accepted, they believe that making time to provide patients with information about their health care should not be considered problematic. With good training, they reckon, providing relevant information to the patient should not unduly prolong the consultation. This calls for increased emphasis by medical trainers on training in 'doctor-patient communication' in the medical schools and residency training programs.

Sometimes patients make decisions that some doctors consider imprudent. I asked them whether such decisions should be respected by doctors. The patients were of the view that whether or not a decision is prudent alone does not determine whether it is worthy of respect. The test, they think, is whether or not the

decision is rational. A rational decision being one based on appreciation of all the relevant facts and a reasonable, normative deliberation prior to coming to a decision. A Jehovah's witnesses' decision to refuse blood transfusion because of his or her faith may appear imprudent to a doctor but does not make the decision irrational. This emphasises the need for doctors to inform and educate their patients.

On the issue that sometimes doctors think that disclosing information to patients particularly about poor prognosis will harm the patient, they believe that patients need to be told about their condition almost always unless they choose not to be told or when the doctor has very good reasons to think that telling the patient will cause significant harm or render the patient incapable of making further rational decisions. I couldn't agree with them more on this. After all, instances where patients are harmed to the extent that they are incapable of making subsequent rational decisions exist only rarely^{30, 31}.

Conclusion

To conclude, respect for individual autonomy in health care is just as important to patients as it is in any other walk of life. Regardless of his or her background, every patient seeks it. Doctors in many parts of the world including Ghana are still paternalistic in their approach to patient care. Patients want doctors to respect their individual autonomy by informing them about their health condition and involve them in decisions about the management of their health conditions.

Respecting patients' autonomy in a busy clinical practice, particularly in a resource limited setting can be challenging but that should not prevent doctors from doing so. When doctors respect their patients' autonomy, patients are happier and satisfied.

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