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Is there an advocate in the house? The role of health care professionals in patient advocacy

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It remains unclear what patient advocacy actually entails and what values it ought to embody. It will be useful to ascertain whether advocacy means supporting any decision the patient makes, or if the advocate can claim to represent the patient by asserting well-intentioned paternalistic claims on the patient's behalf. This is especially significant because the position of advocate brings with it certain privileges on the basis of presumed insight into patient-perceived interests, namely, entitlement to take part in clinical decision making and increased professional standing. Three issues related to patient advocacy will be explored: are patient advocates necessary; what does advocacy entail, and who ought to represent patients in this way—arguments for and against prospective candidates will also be covered. The paper considers whether advocates are necessary since not only can they be dangerously paternalistic, but the salutary values advocacy embodies are already part of good professional health care.

Advocacy is alleged to be a means of safeguarding good patient care. A variety of professionals claim to be best suited for the position, many stating that the role of patient advocate is inherent to their professions. The numerous players have different interpretations of, and applications for, the role of advocate. As a result, it remains unclear what advocacy actually entails and what values it ought to embody. This is especially significant because the position of advocate brings with it certain privileges on the basis of the advocate's presumed insights into the way patients perceive their own interests, namely entitlement and force of input into clinical decision making and increased professional standing. Three issues related to patient advocacy will be explored in this paper. First, is there any real need for patient advocates? Second, if there is such a need, what would patient advocacy entail? I propose to show that this is fraught with conflict between representation and paternalism. And third, who ought to best represent patients in this way? This part of the paper will include exploration of the arguments for and against prospective candidates. Some comparison will be made with the role and duties of lawyers as the conceptual role models for patient advocacy.

Before proceeding any further, I wish to make it clear that I refer to individual advocacy in health care and therefore avoid discussion of patient forums and advocacy groups, which are more political in nature and may not always be able to represent an individual patient. Instead, the notion of advocacy addressed in this paper will cover the needs of individual patients to have their interests represented to ensure considerate decision making and good care.

I. IS THERE A NEED FOR ADVOCACY IN THE MEDICAL CONTEXT?

The answer to this is debatable. There is evidence to suggest that patients require support to ensure their expressed needs are taken seriously and their interests promoted. This was most recently demonstrated by the case of conjoined twins separated by court authority despite their parents' protests, and is perhaps better illustrated in the context of mental health when a patient wishes to stop medication and the doctor disagrees. Nevertheless, on careful consideration, the concept of advocacy imposes a suspicious appearance on the relationship between patients and caregivers, an appearance that

is neither desirable nor necessarily warranted. It suggests that patients and health care professionals are in conflict over best treatment, and that health care professionals may not have patients' best interests at heart.

These may be unduly harsh descriptors of the practitioner-patient relationship. Ideally, the relationship between patient and health care practitioner is one of care, where the concerns and best interests of the patient are at the core of all decisions and interactions. If this is the case, there is no real reason to assume that patients need someone to ensure this on their behalf: rather this is seen as being an inherent part of being a professional health care provider. Such duties are reflected by professional regulatory bodies such as the General Medical Council (GMC) and the United Kingdom Central Committee for Nursing and Health Visiting (UKCC) who recommend that the interests of patients ought to inform every act of the practitioner. The GMC states as much in its handbook *Good Medical Practice*. It urges doctors to "make the care of your patients your first concern," and to: "respect patients' dignity and privacy; listen to patients and respect their views; respect the right of patients to be fully involved in decisions about their care".¹⁰

The Nurses' UKCC recommendations are equally directive toward protecting patients' interests: "act at all times in such a manner as to safeguard and promote the interests of patients and clients. Work in an open and cooperative manner with patients, clients and their families, foster their independence and recognise and respect their involvement in the planning and delivery of care."¹⁸

All of the above are elements consistent with protection of the patient from harm. Most health care professionals assert that they conform to these requirements as a natural part of their professional routines. If this is so then advocates are redundant because professional health care workers are already charged with safeguarding and securing patients' interests. This would indicate that demands for patient advocacy are alarmist, unwarranted, and conflict producing.

Nevertheless, cases like the Alderhey organ retention scandal demonstrate that patients may benefit from having an advocate. Not the least of the reasons to support this is that the very same regulatory documents cited above introduce possible conflicts of loyalty for practitioners. The GMC asks doctors to respond to the needs of *all* patients, which creates a conflict

of interest, especially where doctors are responsible for balancing their own budgets.³ The UKCC is even more explicit in its reference to the good of the community, not just the individual concerned. As a result patients worry that their interests are being balanced against those of others and that prioritising for the purposes of rationing will deprive them of expressed needs and so someone must advocate on their behalf.

These concerns could be resolved by comparing the patient-practitioner relationship with the relationship between lawyer and client, as described by Charles Fried in his 1976 paper. Fried points out that, like the lawyer-client relationship, the doctor-patient relationship is non-utilitarian because: "The ideal of professional loyalty to one's client permits, even demands, an allocation of the lawyer's time, passion, and resources in ways that are not always maximally conducive to the greatest good for the greatest number. ... Both professions affirm the principle that the professional's primary loyalty is to his client, his patient."⁹

Reasons for advocates

Despite this, appeals for patient advocacy persist. These tend to revolve around the inherent vulnerabilities of being a patient and being ill. Patients may need extra support to express and secure their own choices for treatment, especially where the patient's choice may seem bizarre or not preferred by the clinical staff. The advocate can help the patient translate his or her expressed desires into a cogent treatment plan, and help steer the team in a direction preferred by the patient. Even competent patients will usually be excluded from being members of the treatment team. An advocate can be part of the team and therefore ensure the patient's input is heard even when absent.⁶ Also, where patients are not medically trained an advocate could help clarify matters and keep them informed.

There are many other reasons in favour of patient advocacy, especially when patients are frightened, vulnerable, or incompetent. Of course this presumes that the advocate has a clear insight into the needs of the patient as the patient perceives them so that the advocate can properly represent these to the health care team. (Although it is possible for the advocate to act just to ensure the patient's basic human rights are respected.) It also presumes that the advocate is willing to represent the patient's needs as the patient perceives them fairly and without distortion. If this can be proven satisfactorily, then it will give advocates a privileged position in the team by designating them the authentic representative of the patient. These are high but worthy demands, and it remains to be seen how they are met and who is best suited to undertake to meet them.

II. THE ROLE OF ADVOCATE

Part of the problem is that there is no clear picture of what an advocate is, and therefore no regulation to safeguard against abuse if the role goes beyond professional roles and regulations. Seedhouse¹⁶ proposes a "normal sense of advocacy", stating: "an advocate speaks on behalf of another person as that person perceives his interests". But this is not the way the term is used in health care. Lists of essential characteristics can be drawn from the literature, but no satisfactory description of the role of an advocate in the health care setting has been provided. Suggested characteristics include:

1. Inform the patient and promote informed consent^{5 18};
2. Empower the patient and protect autonomy^{5 18};
3. Protect the rights and interests of patients where they cannot protect their own^{3 18};
4. Ensure patients have fair access to available resources^{4 5 12};

5. Support the patient no matter what the potential cost, and
6. Represent the views/desires of the patient and not just her needs.

The first four descriptors of advocacy are not contentious and can be generally beneficent. But, the fifth and sixth are elements not found in the literature and which introduce further elements which highlight two problems inherent in patient advocacy.

Two tensions

Advocacy embodies two related tensions:

1) Conflict between what can reasonably be an expected duty of health care practitioners, and what might be beyond reasonable expectations;

2) The difficulty in distinguishing between what is actual representation of patients' wishes, and what is an assertion of what the advocate believes to be in the best interests of the patient, which would be better described as paternalism.

1) The literature indicates that there is some debate regarding whether advocacy is an essential aspect of professional duty or if its accompanying burdens place it beyond what can reasonably be expected of any professional health care provider. If advocates choose to represent patient perceptions unconditionally, they may find themselves going against their better judgment and being faced with professional or personal compromises that they aren't prepared to make. This can create burdens, such as conflict with other professionals and may be supererogatory. If it does impose such burdens, then advocacy is better described as an admirable choice that should not be expected of individual health professionals. For example, a patient's request for healthy limb amputation for alleged body dysmorphic syndrome might push the limits of most health professionals. If the role of advocate implies unconditional support of the patient's expressed needs it may put the advocate in a position to have to argue for a treatment few of her colleagues agree with.

2) Assuming health care professionals ought to act as advocates, would this invite paternalism? Patient advocates are sometimes described as those who assist the patient through the clinical event by providing clarification, education, and advice. Here it is not as a representative of the patient that the advocate acts, but as a representative of the system. This type of advocacy helps the patient steer through the complexities and miscommunication which can arise as a result of a patient's lack of abilities and/or knowledge. What it fails to do is represent the patient. There may be a risk that well-meaning professionals will use opportunities for clarification and education to manipulate patients into making the "right" choice. So it promotes confusion between a) advocating for what the patient wants, even if this may not be what the professional thinks is best for the patient and b) doing what the advocate believes is in the patient's best interest, even if this overrides the patient's expressed needs.

This is where advocacy walks a fine line between patient representation and paternalism. If the advocate does not adequately represent the patient's own views, but instead supports decisions he believes to be in the better interest of the patient, then he is not acting as advocate but as paternalist, especially when the patient is capable of making decisions for himself. This is, after all, the classic description of paternalism: to override a person's self determined choices on the grounds that doing so is in that person's best interest. Advocacy pursued in this way is morally wrong if it is disguised as representation of what the patient wants. This notion deserves closer analysis.

Patient wishes

It may be difficult to be sure what the patient wants. The best way to find out is to ask the patient, but that is not possible

when, as frequently happens, those who need an advocate are unconscious or incompetent. Those who are unable to express their wishes can benefit from advocacy to ensure their basic rights are respected. A patient needn't be incompetent to benefit from advocacy, however, he may simply be vulnerable or not knowledgeable enough to express his views and expectations. For example, a health provider may decide to act as advocate for a patient with bipolar disorder who wishes to stop taking medication. Significantly however, the professional is not acting as an advocate if the advocate perceives this to be counter to the patient's best interests and defends this position instead of the expressed views of the patient.

Claiming to represent the patient's view while in fact only stating what the advocate believes to be in the patient's best interest, is not necessarily advocacy. Firstly, it does not accommodate knowledge of what the patient perceives her needs to be. Secondly, it could therefore be performed by any health care professional who is committed to the duty of care as it is described in professional guidelines. But, where advocacy is required it is representation of the patient's perspective that needs rescue, not insurance of caring practice—at least not where health care professionals are conscientious about enacting their roles according to the directions of their regulatory bodies. Given that patient wishes and professional judgments will not necessarily harmonise, the advocate's role must therefore be to protect and represent patient-perceived needs and values. Here again Fried's parallel with lawyers informs our understanding of patient advocacy. The patient, like the legal client can be argued to have a right to this kind of unfettered assistance from the advocate because it helps the patient to maintain her: "integrity as a person ... the [advocate] makes his [patient's] interests his own in so far as this is necessary to preserve and foster the [patient's] autonomy..."⁹

Representing patient wishes, rather than what the advocate wishes for the patient, is the best way of protecting the integrity of the person when that person is unable to do this for herself. Otherwise it is paternalism even if it is well intentioned.

The compromise

As a result of these challenges, it must become recognised as morally appropriate for health professionals acting as patient advocates to do all they can to help the patient, and let others worry about the impact this might have on the community, colleagues or other patients. This can entail acting in ways that professionally or personally compromise the advocate, which is no different for the lawyer who represents a criminal. Fried's comparison of the lawyer-client relationship with the doctor-patient relationship may offer a solution for the compromise. His claim is that lawyers must sometimes compromise themselves to help their clients, including at the expense of others. The same may be true of the doctor or other health care professional who assumes the role of patient advocate. It may be disagreeable and antagonistic to do so, but it is necessary for the sake of impartiality and respect for client autonomy. Fried asserts that: "The lawyer acts morally because he helps to preserve and express the autonomy of his client vis-à-vis the legal system. ... Rights are violated if, through ignorance or misinformation about the law, an individual refrains from pursuing a wholly lawful purpose. Therefore, to assist others in understanding and realising their legal rights is always morally worthy."¹⁰

The same can be said for health care professionals who represent a patient's perceived needs even when they are bizarre or compromise the advocate. True representation is morally worthy because it protects patient autonomy in the face of a potentially overwhelming and intimidating health care system. It is therefore the duty of health care professionals to provide this assistance because they are the expert navigators of this system. The patient advocate assists the patient to do

what she would otherwise be unable to do herself. These arguments justify numbers five and six on the list above.

III. WHO OUGHT TO ADVOCATE FOR PATIENTS?

If it is agreed that patients can benefit from advocates, and assuming someone is willing to assume the burdens entailed, then it will be necessary to specify the representative group in advance. Many will seek to take the role, in part for patient care, but also because the rewards of professional advancement and privilege of position in decision making will tempt them. If the designation of patient advocate is not made specific, then conflict can arise among those who believe they are the rightful advocates for the patient. Designation of the advocate in advance will reduce competition later on. Conceptual models of a number of potential candidates for patient advocate are considered here.

Patients as advocates

Patients representing themselves benefit from enhanced autonomy and informed consent. But patients are in varying states of vulnerability and may be unable to represent themselves adequately. Therefore external support may be beneficent, if not necessary.

Family and friends as advocates

Family and friends can know a patient's needs and wishes well, and generally speaking have an emotional investment in ensuring the best for the patient. This makes them informed and deeply committed. But the commitment can be high in demands on time and energy; it may require sacrifice in other areas of their lives, as well as struggles to be taken seriously by professionals (who are also vying for the role of advocate). Also, family and friends may have vested interests in manipulating or misrepresenting the patient, as the outcome usually affects them as well. Thus, there is a danger of covert paternalism, or worse, self serving, when family and friends act as patient advocates.

Professional advocates

Experiments in professional advocacy have been made in Austria and Canada.¹¹ Advocates in these countries are employed to do nothing other than advocate for the patient. Therefore they have no other loyalties and no conflicts of interest. They can be trained and may even have some professional medical training. Their official status would reduce intimidation by the health care setting and protect them from being ignored. But the very nature of a professional advocate creates an adversarial atmosphere between patient and carers that may not be natural and which could hinder patient care. Also, if professional advocates are strangers to the patient they may be incapable of accurately assessing patient values and goals. Finally, it is not clear who will fund the advocates and to whom they will be responsible, for example could they be sued for giving bad advice?

Doctors as advocates

Doctors have often claimed the role and there are sound justifications to support this. It may be a very natural part of their jobs as they do it all the time in the form of treatment decisions. Moreover, general practitioners often have longstanding relationships with patients and therefore have a sound basis for knowledge of the patient's goals and needs. Recent transformations in the UK and in managed care in the US have, however, created conflicts of loyalties between duty to patients and duty to the community.³ Because of this, doctors may be unable to commit fully to advocating for a single patient. In addition, doctors have historically been accused of covert paternalism and thus may not be trusted to respect patient interests as the patient perceives them. Acting beneficently is not necessarily identical with acting in accordance

with patient wishes. Giving doctors official status as advocates could increase their justification to act paternalistically and worsen the situation. Finally, doctors confront special difficulties, that arise for the nurse as well, which may call upon them to compromise themselves in the role of advocate. These will be considered in greater detail with respect to nurses.

Nurses as advocates

The literature contains convincing arguments in favour of nurses assuming the role of patient advocate. Nurses are medically educated, professional members of the team. They tend to spend the most time with hospitalised patients and are therefore more able to assess their needs and aspirations (beyond medical needs). Moreover, the UKCC indirectly endorses the role. But is this right?

First, nurses, like doctors, may have conflicts of interest, as expressed in the UKCC document.¹⁷ The interests of society and duties to the profession may conflict with adequate representation of the patient, for example when a patient requests expensive, experimental, or clinically less preferred forms of treatment.⁴

Second, advocacy implies being prepared to be adversarial and this can promote discord with colleagues and within teams.¹⁸ For example, a nurse who acts as advocate for a patient who wants a bilateral prophylactic mastectomy could find herself in dispute with colleagues over the best interests of the patient. Where professional views of patients' best interests do not coincide with patients' expressed interests, the advocate could find herself supporting the patient at the expense of professional harmony. Doctors face the same problem, but it can be especially challenging for nurses who have traditionally been seen as owing their full loyalties to the doctor. Now the locus of loyalty has shifted toward the patient, it can cause disharmony and disappointment from those who expect the traditional role. This may change over time, but potential conflict with colleagues over patient wishes will be an ongoing problem.

Third, the advocate may be asked to represent a patient's bizarre or dangerous choices, such as those mentioned already, or to represent the patient in ways that compromise the advocate's personal or professional beliefs. The advocate may try to persuade the patient to do otherwise and if unsuccessful may withdraw from advocacy, but that forces us to question whether in doing so the advocate continues to be a patient representative or if her withdrawal is paternalistic. Perhaps it will be necessary to regulate the decision to quit being a patient's advocate in order to protect both patients and those acting as advocates.¹⁸

Finally, at present there is no formal training for nurses or doctors to represent patients in this way.⁸ It is true that the elements of nursing and medical education are useful for these purposes, but people who assume the role of advocate ought to be prepared for coping with the potential hazards and hardships that accompany advocacy. Knowledge of medical law and ethics will surely be useful,¹ but other qualities may not be as easily acquired, for example negotiation and communication skills.

CONCLUSION

Analysis supports the need for patient advocates, especially where patients cannot advocate for themselves. If it is agreed that advocacy is a useful role then guidelines can be drawn up to provide some protection from harm both for the patient and the advocate. A clear description of the role would be useful. It will be necessary to ascertain whether advocacy means supporting *any* decision the patient makes, even bizarre or bad ones. The advocate's response to requests that entail compromise of personal or professional beliefs must also be determined. Clear guidelines for educating potential advocates, must be defined. Protection and support for advocates will be needed. As with lawyers, a mechanism is required for allowing advocates to separate their views from the views of those they represent. A further method for protecting against the dangers of professional discord will be required. And finally, but very importantly, prospective advocates will need to be trained to guard against overriding patient autonomy with paternalistic judgments.

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