

Benefits of patient representatives and advocates



What are patient representatives and advocates, and in what ways do they benefit patients?

There has been an arguable change within the working practices of the healthcare systems in the UK (and elsewhere) in the recent few decades. One can point to the gradual evolution of the general public perception of the doctor / physician from an unchallengeable, unapproachable all-knowing figure embodying benign paternalism at the inception of the NHS to the still knowledgeable, but nevertheless accountable, healthcare professional who has to consider the patient's needs and requirements but can still be capable of making decisions which may not be in the patient's best overall interests. (1) This has been coupled with the ascendancy of other stakeholders, such as the pharmaceutical industry, whose aims and objectives may not always run parallel with the concept of holistic patient care. (2)

One can also argue that the concept of advocacy has risen to the fore in recent years, as a result of such evolutionary processes, with most stakeholders agreeing that the role of the patient advocate is an essential prerequisite of modern healthcare systems and is believed to be a means of safeguarding good patient care. At first sight, this movement could be considered a universal concept of excellence with no downside, after all, patient centred care and patient empowerment and education are considered current ideals in healthcare delivery and surely patient advocacy must be considered a major tool in helping to achieve these goals?

This essay challenges this notion and intends to set out the arguments both for and against this proposition.

There is no doubt that the concept of advocacy has gained credence in the recent past and is considered to be a means of safeguarding standards of good patient care. (3)

It is perhaps unsurprising that a number of different healthcare professional groupings claim the intrinsic right to be patient advocates suggesting, in support of their claims, that their particular branch of the profession has an inherent capability in the role. Closer inspection might suggest that the different professions, and indeed different individuals within these professions, may actually have different interpretations of, and applications for the role of the patient advocate. (4)

The result of this spectrum of beliefs is that there is both confusion and uncertainty as to what advocacy is, or actually should be, what it entails and what values it should have. This is disturbing from an analytical viewpoint, as it is generally agreed that the concept of advocacy brings with it a number of privileges, some of which are largely based on the acceptance of the fact that the patient advocate is presumed to have insights into the way in which patients perceive their own interests, others include an enhancement of the individual's own professional standing.

To expand the first point further. We have used the term " patients perceived interests" to include their perceived beliefs into their rights and protective mechanisms, including their entitlement of force and degree of input into clinical decision making, relating to their own case.

Despite the comments and considerations already presented, we would suggest that inherent in the discussions relating to patient advocacy, will be <https://assignbuster.com/benefits-of-patient-representatives-and-advocates/>

an element which considers whether there is an actual need for the patient advocate. If we are able to demonstrate a need, then we should also consider exactly what are the features that a patient advocate would need to embody and also it follows that we should discuss who is best suited to fulfil the role.

Firstly then, we need to consider whether or not a patient advocate is actually needed in the current mechanisms of delivery of NHS healthcare. Is there actually a need to support patients, to express their perceived needs more vociferously, to ensure that their needs are taken seriously and that their interests are actively promoted?

This is probably best illustrated by considering cases at the extreme end of the continuum of need. We can cite recently publicised cases where conjoined twins were separated by direction of a court despite the protestations and direct opposition of their parents (5). One can also consider a more frequently encountered practical problem, where the mentally ill patient decides to stop medication and the doctor in charge of the case disagrees.

On face value, these types of situations appear to make a fairly unanswerable case for the existence of the patient advocate. On deeper examination however, one can take the view that the concept of advocacy can appear to impose certain difficulties in the obvious and necessary relationship between the healthcare professional and the patient, which may give it an appearance which is possibly neither required, desirable or actually merited. The presence of an advocate in the therapeutic negotiations

between doctor and patient carries with it an implied suggestion that the two parties are not only in conflict over the decisions relating to the best (or most appropriate) treatment for the patient, but that the professionals may not actually have patient's best interests in sight and may actually have ulterior motives from which the patient needs to be protected.

Clearly this is an extreme position, and may well not be representative of the vast majority of doctor-patient interactions. We do not seek to argue against the fact that the ideal (and probably normal) relationship between doctor and patient is anything other than one of holistic care and that the healthcare professional takes the requirements and desires of the patient fully into account when formulating care plans and carrying out professional interactions. If we are correct in the assumption that this is actually the case, then it follows that, in the normal doctor-patient interaction, there is palpably no need for a patient advocate as this can be interpreted as being seen as an inherent part of the professional activity of a healthcare professional. This point of view is enhanced by an examination of the advice given and regulations imposed by the various professional regulatory bodies in the UK. For example, the GMC gives advice to all registered doctors:

make the care of your patients your first concern, 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. (6)

The United Kingdom Central Committee for Nursing and Health Visiting (UKCC) also add that their recommendation is that their registered

professionals should “ ensure that the interests of patients inform every act of the practitioner” (cited in 7). Nurses specifically are directed to:

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.” (8)

All of these arguments and professional statements are consistent with the Ethical principal of Beneficence, which effectively charges all healthcare professionals with a duty to protect the patient from harm. It is probably beyond dispute that the vast majority of healthcare professionals, if asked, would suggest that they would adopt these principles in their professional work. If this is the case, then one could reasonably argue that there is no need for the patient advocate since the professionals in the healthcare system are already aware of their responsibilities in this respect and that an insistence on a requirement for a distinct and separate role of a patient advocate could be considered unnecessary, alarmist and fraught with the potential to produce conflict. (9)

Part of the discrepancy in these viewpoints becomes obvious when one considers the right of the individual patient and the collective rights of all patients. Healthcare professionals have a duty of beneficence to the patient that they are treating, but there is also a wider responsibility to “ The Public Health” in a general sense, and this certainly is a major source of potential conflict. This is not an academic argument but a very practical one. Closer examination of the documents cited above shows that, for example, the GMC

requires doctors to consider and respond to the needs of “ all patients” - not just the individual patient that they are treating at the time. This clearly has a huge potential for producing conflict when, since the advent of initiatives such as Fundholding, many doctors also have varying degrees of responsibility for running their own budgets which then directly reflect on patient care. (2).

Such conflicts enhance the perception, by the public at large, that their own perceived individual interests are being balanced by the doctor (or other healthcare professional) against the interests of other factions. If the doctor needs to prioritise treatment (as inevitably they must in a rationed service such as the NHS), the patient may believe that their own needs are being subsumed by a consideration of the greater public good, thereby depriving them of both autonomy and the possibility of achieving those treatment goals that would otherwise have been set for them. (10)

One only has to consider the furore surrounding the Alderhey organ retention issue to appreciate that such a view has a considerable validity and topical resonance.

This issue has been addressed by a number of authorities in the past. In a milestone paper on the issue, Fried compared the role of the advocate in the medical field with the eponymous role in the legal profession. (11) He drew a number of analogies between the doctor - patient relationship and the relationship between the lawyer and the client, describing them both as 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.

The case would therefore seem to be made for the presence of the patient advocate, although it is neither as transparent nor as clear cut as it might appear on first consideration.

If we now consider the argument from a different perspective, we could look at the reasons why the calls for advocacy still persist in the literature.

The NHS Plan 2000 called for the acceptance of multidisciplinary team working and the adoption of the concept of the healthcare team. As a result of this initiative, decisions relating to patient care tend to be made more often by a multi-input team of professionally qualified individuals than by one individual alone, particularly in the hospital setting (although the same comments are arguably less true in a primary healthcare team setting). (12)

In general terms, such decisions are made when the patient is typically ill, vulnerable or may have diminished degrees of (legal) competence. In circumstances such as these, it is easy to see why some authorities can argue that the patient may need a degree of extra support (possibly both practical and moral) to be sure that their own wishes, preferences and choices are heard, weighed and fully considered by the team. This is particularly the case where the patient's choices may appear to be bizarre,

irrational or counterintuitive. Certainly it is the case when the patient's choice is not the one that is preferred by the clinical staff.

Authorities such as Seedhouse suggest that, in these circumstances, the patient advocate can assume the mantle of helping the patient translate their expressed desires into a cogent treatment plan and to help to steer the healthcare team in the direction preferred by the patient. (13).

The practicalities of this function being invested in a professional member of the treatment team become obvious when one considers that it is still normal practice to exclude the patient, even intelligent and informed ones, from the discussion forum where treatment plans and goals are formulated. The advocate can thereby ensure that the patient's wishes and desires are still represented even in the circumstances when the patient is absent. (14). The other side of this argument is that the dual role of the patient advocate is also to report back to the patient the decisions of the team in a language and a context that is appropriate for the patient's level of comprehension, thereby keeping the patient informed of decisions made.

This degree of communication also provides an obstacle in the arguments supporting advocacy because it implies a full understanding and clear insight, by the advocate, of the patient's needs (as the patient perceives them) so that the advocate can present them to the healthcare professionals in the team. Incomplete understanding of these issues can clearly lead to distortion and bias which undermines the usefulness of the arrangement.

We alluded earlier to the fact that there was " both confusion and uncertainty as to what advocacy is, or actually should be". Before we

<https://assignbuster.com/benefits-of-patient-representatives-and-advocates/>

examine the subject further, it is useful to consult the literature for authorities on the subject. We have already presented Seedhouse's view that "an advocate speaks on behalf of another person as that person perceives his interests". This may be true, but it is not the way that advocacy is generally employed in the medical literature and medical practice.

A brief overview of the literature on the subject will reveal a number of different interpretations of the essential characteristics of a patient advocate specifically in the healthcare setting and these include:

Inform the patient and promote informed consent (8)

Empower the patient and protect autonomy. (12)

Protect the rights and interests of patients where they cannot protect their own. (3)

Ensure patients have fair access to available resources. (15)

Support the patient no matter what the potential cost (4)

Represent the views/desires of the patient and not just their needs (4)

If we follow Schwartz's analysis it would appear that advocacy has two related tensions:

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

The difficulty in distinguishing between what is actual representation of patients' wishes, and what is an assertion of what the advocate believes to

<https://assignbuster.com/benefits-of-patient-representatives-and-advocates/>

be in the best interests of the patient, which would be better described as paternalism.

The logical conclusion from the first point is that there is a dichotomy of opinion as to whether advocacy is an essential ethical professional duty or whether it is a burden which is not an essential prerequisite, but a choice that can be made voluntarily.

It follows, from the arguments already set out, that if a patient advocate assumes the mantle of agreeing to try to present the patient's perceptions of their situation and needs, unconditionally and accurately, then they may find themselves in a dilemma of discovering that the patient's choices conflict with their own and require professional compromise which they may be unwilling to make. On a different level, it may impose a burden of anticipated conflict with other professionals. This may put the patient advocate in a situation which is clearly at odds with the views and guidance published by the profession's governing bodies expressed earlier. For these (and other) reasons, we could therefore argue that advocacy may be better described as an admirable choice rather than an expectation and duty of healthcare professionals. (16).

Wu (17) gives a good practical illustration of this point. How should a potential patient advocate respond to a request for an amputation of a healthy limb from a patient suffering from a body dimorphic syndrome? One might suspect that such a request would produce considerable conflict in the professional practice of the advocate, quite apart from the almost certain conflict that it would arouse with most other professionals when this view

was expressed. The assumption of such a role in these circumstances would suggest that the advocate would have to exhibit unconditional support of the patient's expressed needs and the ability to suppress their own professional feelings on the subject.

The concept of paternalism is commonly confused with advocacy in the literature. Some authorities refer to advocacy (wrongly in our view) as the action of assisting a patient through their illness trajectory, or particular clinical procedure, by acting as a resource to provide clarification, advice and education.

Halbach (18) suggests that this type of activity is not advocacy for the patient, as it is not as a representative of the patient that the advocate is acting, but as a representative of the healthcare system and clearly this is quite a different concept. It is clearly admirable to help and guide the patient through the complexities of a medical procedure and to minimise the possibilities of miscommunication that can occur if the patient's own intellectual capacities and abilities are limited. This type of "advocacy" does not however, represent the patient, Indeed, one could argue that such paternalism may be inadvertently (or even overtly) utilised as an opportunity of the albeit well meaning healthcare professional to bias or frankly manipulate the patient into making the preferred choice.

This type of activity, although promoted as one of the attributes and requirements of advocacy, does little to clarify the confusion that exists in this area, as it is essentially doing what the healthcare professional believes is best for the patient, or in the patient's best interests, even though it may

actually override the patient's expressed needs. It needs to be contrasted with the definition of advocacy that we are arguing in this essay which is advocating what the patient wants, even if this goes against what the healthcare professional actually believes is best for the patient.

Obviously there are a number of clinical situations where advocacy and paternalism may appear to overlap, but a critical analysis of the situation should allow a clear, albeit fine, distinction between these two states. If the overriding analysis is that the advocate is essentially supporting the decisions that they believe are in the best interests of the patient, but not necessarily putting forward the views of the patient, then the action is paternalistic. This difference is all the more important when the patient is actually capable of expressing their own considered views in any event

Malin (19) reminds us of the generally accepted definition of paternalism which is to override a person's autonomously self determined choices on the grounds that they believe that it is in the patient's best interests. If this is presented as paternalism then so be it. If it is presented as advocacy, then it is morally and ethically wrong.

There are occasionally circumstances in which it is not possible to be sure of exactly what the patient wants. The paradox is that those who are able to express themselves are probably least likely to require an advocate and yet those who are actually in the greatest need of advocacy are those who may be unconscious or legally incompetent.

If we embrace the arguments that we have set out so far, it follows that the healthcare professional who is acting in the capacity as patient advocate

<https://assignbuster.com/benefits-of-patient-representatives-and-advocates/>

must do all that they can to help the patient. This is morally appropriate and recognised as part of the responsibility of the office. This is in direct distinction from considerations relating to the rest of the community, ones colleagues or, for that matter, other patients, which must not be considered if they are antagonistic to the position that the patient finds themselves in.

The thrust of this argument clearly means that there may well be situations encountered, which may professionally, or even personally, compromise the activities of the patient advocate. We can return to Fried's analogy with the criminal lawyer advocate in an attempt to find a compromise solution. Later in his article, Fried points to the fact that lawyers have to compromise themselves to provide optimum help for their clients and this includes acting knowing that they may compromise the position of others. As we have already outlined, a healthcare professional who agrees to be a patient advocate, may have to antagonise others if they are to carry out their duties impartially and with a proper ethical respect for client autonomy. (20)

Fried takes his rationalisation to the limits when he states:

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. (11)

If we accept the validity of this argument then we can also accept the corollary can apply to healthcare professionals. True representation is, in Fried's terms, morally worthy and can be justified because it protects patient autonomy in the face of a "potentially overwhelming and intimidating healthcare system" (21)

To bring this thread of argument full circle, we can point to the fact that it can therefore be considered part of the duty of the healthcare professional to provide assistance and guidance because, by virtue of their training knowledge and expertise, they have the experience to be expert navigators in the healthcare system. In the words of Schwartz

The patient advocate assists the patient to do what they would otherwise be unable to do themselves.

These arguments justify numbers five and six on the list above.

Having established both the need and the parameters of the role of the patient advocate, we should now consider the qualities and the position of the patient advocate in general terms.

The patient may be in a position to fulfil the role adequately themselves. In theoretical terms this may be seen as the best possible outcome, as clearly the ability to give informed consent is a natural sequel to the ability to represent oneself. In practical terms this is seldom accomplished as, by the very nature of being a patient, there is an implication of the state of illness and this brings with it a degree of vulnerability in all but the most stoic of individuals. Few patients have sufficient knowledge to be able to assimilate

all that is told to them in the context of their illness and may also therefore benefit from having an “ external” or uninvolved advocate.

The friends and family of a patient are natural candidates for the role as they generally know the patient as a person, they are familiar with their needs and desires and can (sometimes) be relied upon to have an empathetic desire to ensure the best outcome for the patient. Such candidates may not be universally altruistic however, as there may be the possibility of family and friends having a vested interest in a less than optimum outcome of a patient’s illness. They may therefore be perceived as being at risk of overtly manipulating the situation or misrepresenting the patient, as there may be an outcome-related benefit for the family member. Inevitably there will be a commitment to a great deal of involvement, both in terms of time and emotional energy, which may be generously given, but should not be taken for granted. Such comments should obviously be considered by the healthcare professionals involved, but this should not be allowed to blind them to the common clinical experience that the vast majority of friends and family who wish to have an input in these circumstances are often both informed (about the patient) and deeply committed on their behalf.

We should draw attention to the fact that some cultures and healthcare systems have experimented with the concept of the professional patient advocate, particularly in the area of psychiatric disease. (22). In countries such as Canada and Austria, patient advocates are trained and employed specifically to fulfil this role and nothing else. The theory being that by doing this there is no conflict of interest, and the element of paternalism is effectively eradicated from the scenario. Such advocacy should be in its

purest form therefore with undivided loyalty to the interests of the patient and no professional bias or personality issues. In such a context, it is believed that there will be less intimidation or inhibition by medical beliefs or dogma and their official status will prevent them from being ignored.

The studies that have been carried out in this area have revealed a downside which may not have been widely anticipated. The presence of a designated and professional patient advocate in the decision making process has the ability to engender an adversarial atmosphere where healthcare professionals may adopt a defensive stance which is not optimal for efficient and effective patient care, particularly in the field of psychiatric illness. (23).

Practical difficulties ensue when personnel, who may not have wide experience in assessing and handling people in the course of an illness trajectory, may actually be unable to accurately assess the patient's own goals, values and beliefs. Because such projects are still in their infancy, a number of other potential practical problems have yet to be resolved. The issue of responsibility and accountability is not formalised. One has to question the options open to a patient who finds that they believe that their professional advocate has given them bad advice or poor representation. There are, as yet, no formalised pathways for redress.

Doctors have a track record of fulfilling the role as the patient advocate. To an extent, it may be considered a natural extension of their " job description" and role in the community. Some doctors may be more fitted than others by virtue of their particular position in the medical hierarchy, their personality or their disposition towards particular patients. For example

the GP is likely to have built up a relationship over the years with many of his patients and will know them, their families, their wishes, and their personality intimately. One might think that they might be prime candidates for the job. Equally a specialist who may have no knowledge of the patient and may be (for example) an excellent technician in his field but suffers from an inability to communicate well with patients may be a very poor candidate.

In addition to these considerations we have already referred to the potential conflict of interests which have arisen in respect of GP Fundholding in the UK where the GP has a theoretical, and in some cases, real problem in balancing his ethical duty to the patient with his financial responsibilities to the community at large (2). For this reason, some doctors find that they cannot realistically act for the interests of the individual patient when they are overtly conscious of their obligations to the pressures of funding a balanced service for the community at large.

Some doctors also have cultivated a paternalistic approach to their practice. This is an observation and not intended as criticism, as some would hold that it is an approach which works, and is appreciated by certain sections of the community. (24) In the context of this essay however, for reasons which we have set out in detail above, it is an approach which is not compatible with our definition of advocacy. Such an approach is capable of not being trusted to set out the patient's interests - as the patient perceives them. As we have illustrated earlier, it is more likely to be set out as the doctor believes would be best for the patient, and this removes the possibility of true patient autonomy. (25) Acting in accordance with the Principle of beneficence does <https://assignbuster.com/benefits-of-patient-representatives-and-advocates/>

not necessarily imply that one is acting in accordance with the patient's explicit wishes.

We have also considered peripherally, the fact that, in acting in a capacity as an advocate, a doctor may find certain other professional conflicts of interest and may therefore find his capacity to act as an unbiased advocate severely impaired.

Traditionally the nurse has frequently filled the role of the patient advocate and, on face value, it would appear that the nurse is possibly in the most favourable position to fulfil the role. (26) The nurse has a professional medical training and is well versed with healthcare procedures and practicalities. In a hospital setting, they are the healthcare professionals who tend to spend most of their professional time in direct contact with the patients and are therefore perhaps best placed to be able to holistically assess their needs, aspirations and goals in the widest connotation of these terms. Their professional body (the UKCC) endorses their involvement in this role.

The converse of these points include the fact that the nurse, like the doctor, has potential conflicts of professional interest, not often the financial considerations that may fall to the doctor, but other considerations, where there is an antagonism of a professional position where there is a duty to society in general, or perhaps a duty to the profession and the duty to the patient in the role of a patient advocate.

A topical situation could be illustrated by the debate over Herceptin (Trastuzumab) which has not yet been fully evaluated and costed by the <https://assignbuster.com/benefits-of-patient-representatives-and-advocates/>

regulatory authorities, but is in demand by sufferers of advanced forms of breast malignancy. If a nurse was acting in the capacity of an advocate for such a patient, one would have to consider how she would resolve her professional difficulties in recommending a drug that is not yet fully licensed, her duty to society in general to uphold the regulatory pharmaceutical mechanisms and her obligations to the patient who is telling her that she believes that this drug is her best chance of long term survival. (after 27)

The NHS Plan 2000 sets out to promote the “seamless interface of care” between healthcare professionals together with concepts such as multidisciplinary team working. (28) Such concepts are difficult to reconcile with what may transpire to become an adversarial situation.

As we have already examined this type of situation in respect of doctors, we shall therefore not set it out again. It is however, appropriate to observe that this adversarial element may be particularly problematic for the nurse as working practices in the past have required appropriate deference to the doctor, and this shift of loyalty may cause particular difficulty in those healthcare professionals who are uncomfortable with this apparent change of stance.

Lastly, we note that the formal nursing and medical training in the UK does not currently contain any element of specific learning about this topic. (12). Clearly the general knowledge relating to the workings of the healthcare services and the profession specific training are good preparations for the role but it is quite possible to become qualified without becoming aware of the potential problems associated with advocacy that have been set out

here. Medical law and ethics are traditionally poorly represented in the professional curriculum (29) as is specific training in communication skills and the art of negotiation.

There is one point that is common to all potential patient advocates that we have not yet addressed. We have considered the fact that the patient may make seemingly irrational, bizarre or idiosyncratic choices may place the patient advocate in a difficult position. If this is the case,