



The Issues of Incapacity to Give Consent

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Abstract

The words capacity and competence are often used interchangeably within the modern day, however strictly speaking competency is the legal term for capacity to give evidence. Those above the age of 18 are presumed competent unless otherwise shown by a court of law. Capacity has a more pragmatic use in that it refers broadly to the ability to consent. This ability is subsequently assessed by various methods. The issue of consent has become an extremely contentious issue in recent years especially due to the Alder Hey and Bristol scandals. The issue of autonomy is becoming more and more scrutinised. It is for this reason that incapacity to give consent becomes a minefield of ethical dilemmas balanced between medical paternalism and patients rights and ability to choose between what treatment they would and would not like. Autonomy has become a core principle within the medical field although some ethicist argue that it is for a patients autonomy that the profession exists serving in order to maintain it. This review attempts to highlight the reasons for a limb amputation and the issues surrounding the incapacity to consent.

Introduction

The words capacity and competence are often used interchangeably within the modern day, however strictly speaking competency is the legal term for capacity to give evidence. Those above the age of 18 are presumed competent unless otherwise shown by a court of law. Capacity has a more pragmatic use in that it refers broadly to the ability to consent. This ability is subsequently assessed by various methods. The issue of consent has become an extremely contentious issue in recent years especially due to the Alder Hey and Bristol scandals. The issue of autonomy is becoming more and more scrutinised. It is for this reason that incapacity to give consent becomes a minefield of ethical dilemmas balanced between medical paternalism and patients rights and ability to choose between what treatment they would and would not like. Autonomy has become a core principle within the medical field although some ethicist argue that it is for a patients autonomy that the profession exists serving in order to maintain it.

This review attempts to highlight the reasons for a limb amputation and the issues surrounding the incapacity to consent.

Limb amputation and decision to operate

Limb amputation may be undertaken for a wide variety of reasons. The two most prevalent causes are vascular occlusive disease and infection secondary to diabetic foot ulceration. Other infrequent causes include malignancy, trauma and congenital malformations. Lower limb amputations are far more common due to the underlying disease affecting this area most. Approximately 80% are over 60 with factors such as heart, respiratory and neurological disease compromising their quality of life post-op.

An estimated 3% of patients experiencing intermittent claudication progress to critical limb ischaemia and subsequent amputation. 25% of those with chronic limb ischaemia (approximate incidence of 500 to 1000 per million) will go on to have amputations.

The elderly are a group whose quality of life greatly depends on outdoor activities such as gardening, walking, travelling and the ability to be independent with regards to cooking and washing. It is for this reason that a fundamental aspect in issuing the surgeon with consent is their ability to mobilise after the operation.

A limb amputation is a last resort for patients with limb ischaemia and diabetic causes. It is often considered a hypothetical situation by most people, so when patients come to hospital with the prospect of a loss of a limb it can be both shocking and disturbing for them. Effectively when a patient is competent and has the capacity to assess the scenario it is their choice whether to go ahead or not. A recent patient at the Royal Liverpool Hospital had a gangrenous foot secondary to vascular disease secondary to diabetes. His options were between having an amputation of his foot and doing nothing with death being the final consequence. Interestingly he refused the treatment and acknowledged when asked that he was dying. The twist to the story is that his foot is healing up nicely.

Rehabilitation after limb amputation also plays a key part in a patient's decision to amputate.

Rehabilitation classically consists of nine separate areas 12.

- 1) Pre-operative assessment of medical and body condition, discussion of risks and benefits and subsequent prosthesis attachment.
- 2) Amputation surgery
- 3) Post surgical in the acute stage including things such as phantom pain management, physiotherapy, psychological support 6
- 4) Preprosthetic including physiotherapy for muscle strengthening exercises and maintaining a patients sense of control over the limb.
- 5) Prosthetic prescription requiring a team's consensus.
- 6) Training the patient how to cope with the prosthesis and how best to use it.
- 7) Integration with society including resumption of their pre amputation roles within the community and indeed their families.
- 8) Vocational rehabilitation for change of jobs or further educational training
- 9) Follow up in a clinic to assess the patient's ability to function and how medically fit they are.

All these areas need to be explained to a patient before hand since the knowledge of having follow-ups may make the patient feel as if they are going to be supported after the amputation and may ultimately lead them to a decision of an amputation. Issues such as co morbidity may also affect their decision.

Often in clinical situations surgeons face ethical dilemmas when choosing to amputate, these situations arise when for example a patient may have not have the mental ability to give consent. Many patients undergoing amputation are elderly who may be demented or incapacitated in some way. The decision that the surgeon makes is littered with difficulties and becomes a tug of war between different principles.

Issues surrounding capacity to give consent

Capacity to give consent will always be a contentious issue such is the nature of ethical dilemmas. The inability to give consent is dependent on two main aspects. One is whether the incapacity is acute or chronic and if acute will the patient get better in order that consent can be obtained (for example in patients with hypoxia or a UTI) or is treatment immediately necessary (fig 1).

A survey was recently conducted in America suggested that although orthopaedic surgeons knew most of the ethical issues involved there was an inappropriate level of understanding towards the issue of consent and the capacity or incapacity to give

consent. It may be that the need for specific physician education regarding these issues is becoming more and more paramount.

The issues of incapacity and consent can be tackled using various models, however the most comprehensive one seems to be the 'Ethical Grid' proposed by David Seedhouse.

The ethical grid is based upon the four principles of autonomy, beneficence, non-maleficence and justice. These are expanded into various headings taking the form of a grid.

The most fundamental point of consent is autonomy. In incapacitated patients the level of autonomy is effectively non-existent. They by definition should lack the ability to communicate a choice (in any way), understand the relevant information, appreciate the situation and the consequences and should be able to manipulate information rationally. Four clinical scenarios should alert the doctor to suspect the clinical decision making ability of the patient. Two areas were mentioned above, that of an acute change for example due to hypoxia and the second being a chronic risk factor such as dementia which may impair their ability to choose between treatment options. The other two scenarios would be if a patient refuses treatment or if a patient hastily rushed into a decision. By stating someone no longer has the capacity to decide and by extension his or her autonomy is non-existent the physician puts him/herself into a vulnerable position. For the doctor to decide that this scenario has occurred they must be certain that the patient is incapacitated, this decision becomes even more difficult in dementia as many elderly people with mild dementia may still retain the ability to choose an appropriate treatment option. It is for this reason that several assessment options are available to the physician, these include the mini-mental state examination, abbreviated mini mental test score, Felix post unit questionnaire, Clifton assessment procedures for the elderly, the mental status questionnaire, the blessed dementia scale and Weschler memory scale. Without a full neuropsychological assessment, a patients cognitive functioning cannot be elucidated. In clinical situations most doctors who initially assess capacity are PRHOs; who usually use the Mini Mental state examination. It has been illustrated that the mini mental state examination has 82% specificity with respect to dementia. Its speed and ease and ability to test functioning in several domains make it a popular choice. However for informed consent it was shown that the most effective test for assessing competence and postoperative cognitive dysfunction was the Blessed Dementia Score in which a two-stage format

is employed, the time constraints within the NHS may prevent this form of assessment being appropriate in the hospital setting.

The next issue of capacity is that of who is best appropriate to undertake the assessment? In reality the PRHO is the one first in contact with the patient in the hospital setting and for this reason pragmatically I would be difficult to make senior doctors to assess the patient. Focus should be on PRHO education in order that they can easily spot those with reduced mental capacity. For those with chronic dementia, their GP is the best person. Their GP may also have more time to employ more specific and sensitive methods of assessing capacity.

Once the patient has been assessed it is important that if they are competent that their autonomy should be respected, at a minimum consent forms should have the nature of the procedure including whether it is diagnostic or therapeutic, the risks involved especially those that are severe and likely to occur, benefits of the procedure and alternatives to the procedure along with their risks and benefits; these should all be explained in a clear and concise fashion. These underpin the art of informed consent and should be presented to anyone who has the capacity to decide regardless of age, sex, race or culture. It is a well known principle that consent is a process as opposed to a single signature on a piece of paper but pragmatically this means subsequent tailoring of the method of obtaining consent for example with pictures and diagrams if necessary. It must also be borne in mind that people with dementia may have the ability to consent in certain areas but not in others. For certain patient's videotapes and other decision aids may facilitate the process of consent although these aids are more relevant to researchers who wish to recruit subjects.

Regarding autonomy, if the patient has become acutely unwell requiring treatment it is usual if it is not a life and death situation for the patient to regain capacity and by extension his autonomy. The question arises as to how long one should wait? If the treatment is immediately necessary then should we go ahead? This issue has been dealt with by the legal system stating that two physicians should be present and sign the consent form declaring the reasons for the patient's incapacity and why treatment is needed. The issue of autonomy may be confounded by an advance directive. At the current moment, British Law states that advance directive should be considered but should not be the fundamental basis upon which a decision is made. The circumstances of such a directive would be unknown and the physician must balance the advance directive with the issues of best interest. However it

may be that one could argue that the patient knows what is in their own best interest and hence if an advance directive is present then one should abide by it but then as the Lord Chancellor stated "the patient has to look into a crystal ball and try to guess all the eventualities that may ensue in the future". It has also been shown that the capacity to make an advance directive is dependent on IQ. The issue of autonomy is further confounded by the legal status of Enduring Power of Attorney. Although this legislation only allows a specified proxy to deal with financial matters of an incapacitated person a new piece of legislation has been proposed termed Continuing power of attorney, which will allow the proxy to make health care decisions.

It is good practice for the physician to include various health care professionals in the decision to treat especially with respect to surgery; the anaesthetist may be heavily involved. It is also courteous to involve the relatives in the decision, as they may be the best ones to decide what the patient may want, although research has shown that this is not usually the case. It is clear that the role of a proxy is becoming more and more inevitable, there are three subdivisions that the surrogate can fall into when deciding a particular treatment:

- a) Substituted Judgement – where the surrogate tries to imagine what they would do if they were in the patient's position.
- b) What would be the best for the patient – this is to decide between various options and say what would be best – it may take into account the patient's needs or relate to their previous QOL.
- c) Reasonable Person Standard – This is where a surrogate may say that their QOL was poor prior to the current illness or they have huge co morbidity issues that it would be better if treatment were withheld.

The Bournemouth case in 1997 in which an autistic patient was detained informally at Bournemouth hospital because of his agitation was challenged. It was successfully argued that it would be legal only if he was detained under the mental health act 1983. However the subsequent implications would have meant that any elderly patient lacking the capacity to consent to treatment would have had to be detained under the mental health act for further treatment. The decision was subsequently overturned by the House of Lords. The new Mental health act from Europe and the European convention on human rights could easily bring the Bournemouth case to the surface again especially with specific statements such as 'no one shall be subject to lawful detention without the speedy decision of the courts.

What of the principles of serving a patient's needs first

if neither their autonomy is present nor can it be created via another method like an advance directive or waiting until an acute episode passes. This issue of serving their needs first may sometimes be in contradiction with their best interests. According to the European convention on Human Rights everyone has the right to life, needs such as oxygen, food are ultimately a basic right. The issue of active treatment may be debated as a need. On one hand the right to life requires medication be administered although others argue that this is not in the patients best interests. A patient may often be extremely ill and prognosis is extremely bad. In these circumstances instead of making the patient undergo surgery or continue medication/ conduct active procedures people argue that the patient be left to die in dignity. This line of argument may be extended to those who suffer from severe dementia where some say that the end of ones biographical death effectively means the end of ones true life as all that then remains is 'a mere locus of transient sensations. It then follows that since the patient cannot experience anything meaningful then it is in their best interest to merely die in dignity without any fuss. Another argument is why should one invest resources and time into patients such as these especially with the burden ever increasing upon the NHS. One may debate that an elderly patient is similar to a child except a child has potential to contribute to society in the future, one who is biographically dead continues life without further potential is there a logic to await a natural death when they are effectively dead anyway? Many philosophers argue that life and death are in reality terms for biographical life and death.

Based upon the Hippocratic oath and the fundamental moral principle of 'Thou shalt not kill' it is upon the one who insists on the above philosophy to prove that a particular patient is in truth biographically dead. However this scenario is practically impossible since even with severely demented patients, who is to say that just because their conversations or experiences are different to ours that they do not contain redeeming experiences? It is for this reason that senicide is to be avoided, the debate will undoubtedly continue – 'in perceived economic hardship the unspeakable becomes an option'.

From the above the debate about the equality between the youth and elderly is raised. Would we be debating this issue if the patient were younger? A drug addict? A smoker? the question of 'where and when do we stop' comes into mind.

The issues of minimising harm and doing most good is covered above and relates to all the issues involved with the patient. One can always argue that carrying out a limb amputation on an extremely ill patient is

correct based upon the basis of 'thou shalt not kill' but then one could equally argue that a major operation would increase the chances of someone dieing especially if there coexisting diseases. These issues involve a delicate balancing act between these two principles and come down to expert clinicians who are able to assess each situation on an individual basis and make decisions about subsequent treatment options.

As a surgeon especially when one reaches the level of registrar, the focus is upon your ability to conduct operations and your logbook. This can be a dilemma in itself; one could argue that to it may be beneficial to amputate someone's limb to give the registrar experience since the patient is liable to die anyway. This experience will then be used to benefit society when other amputations are necessary. Does the benefit to society outweigh the rights of an incapacitated person? Many in the current climate of capitalism would argue yes however the ethicists may argue the contrary maintaining a patient should be respected in their own right and that they effectively own their bodies and no one should violate it even if they do not have the ability to either express their consent or dissent to treatment. Many historians, may argue that this is an approach from the Middle Ages where human dissections were discouraged under Christian and a mis-application of Islamic law, which severely hindered the progression of medical science. From these issues raised it follows that there needs to be a body that issues guidelines. The current guidance issued by the GMC is as follows;

19) You must work on the presumption that every adult has the capacity to decide whether to consent to, or refuse, proposed medical intervention, unless it is shown that they cannot understand information presented in a clear way. If a patient's choice appears irrational, or does not accord with your view of what is in the patient's best interest that is not evidence in itself that the patient lacks competence. In such circumstances it may be appropriate to review with the patient whether all reasonable steps have been taken to identify and meet their information needs. Where you need to assess a patients capacity to make a decision, you should consult the guidance issued by professional bodies,

20) Where patients have difficulty retaining information, or are intermittently competent to make a decision, you should provide any assistance they might need to reach an informed decision. You should record any decision made while the patients were competent, including the key elements of the consultation. You should review any decision made whilst they were competent, at appropriate intervals before treatment

starts, to establish that their views are consistently held and can be relied upon.

21) No one can give or withhold consent to treatment on behalf of a mentally incapacitated patient. You must first assess the patient's capacity to make an informed decision about the treatment. If patients lack capacity to decide, provided they comply, you may carry out an investigation or treatment, which may include any treatment for any mental disorder, that you judge to be in their best interests. However if they do not comply, you may compulsorily treat them for any mental disorder only within the safeguards laid down by the mental health Act 1983, and any physical disorder arising from that mental disorder, in line with the guidance in the code of practice of the mental health commission. You should seek the courts' approval for any non-therapeutic or controversial treatments, which are not directed at a mental disorder.

Conclusion

For a surgeon the decision to operate is becoming more and more difficult especially when littered with scenarios such as the incapacitated patient. The law is clear that in the circumstances where a patient lacks competence, two qualified and senior doctors should 'consent' on behalf of the patient taking into account the opinions of anaesthetists, junior doctors, nurses involved with the patient, carers and relatives. The surgeon should also consider any Advance Directives written, when it was written, what the implications of the directive are and whether it is in line with the surgeons own clinically experienced views. With the new Human Rights Laws in Europe the surgeon must continually be aware of what the law is saying. It is still unclear about the effect of these acts but it is true that these issues are liable to become more complicated. The surgeon must regularly review guidelines issued by the GMC with regards to these issues.

Authors Contribution(s)

Written to highlight the difficulties in obtaining informed consent.

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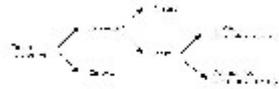
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Illustrations

Illustration 1

Capacity flow diagram



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