Resurrecting autonomy during resuscitation - the concept of professional substituted judgment

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Abstract

The urgency of the resuscitation and the impaired ability of the patient to make a reasonable autonomous decision both conspire against adequate consideration of the principles of medical ethics. Informed consent is usually not possible for these reasons and this leads many to consider that consent is not required for resuscitation, because resuscitation brings benefit and prevents harm and because the patient is not in a position to give or withhold consent. However, consent for resuscitation is required and the common models employed for this purpose are presumed consent or consent from a patient proxy. However, if we are to honour the principles of respect for patient autonomy, as well as beneficence and non-maleficence, when starting and continuing resuscitation we must try and achieve the best balance between benefit and harm from the patient's perspective. The concept of professional substituted judgment involves the resuscitators gathering as much information about the patient as they possibly can, including any previously expressed attitudes towards such a situation, and combining this with their acquired professional knowledge of the likely benefits and harms of the resuscitation endeavour and then exercising their moral imagination, imagining themselves as the patient, and asking "would I want this treatment?" By employing professional substituted judgment resuscitators should recognise when the balance of benefit and harm becomes unfavourable from the patient's perspective and at this point they have a moral obligation to withdraw resuscitation as they can no longer presume the patient's consent. In this way the principles of beneficence, non-maleficence and respect for patient autonomy are more favourably balanced than under other resuscitation decision making processes.

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(beneficence) and doing no harm (non-maleficence) has pervaded medical practice until recent times. Tom L Beauchamp and James F Childress² expound a principled approach to bio-medical ethics and specifically they promote the principle of autonomy while accommodating the traditional principles of beneficence, non-maleficence and justice.

There are two components of resuscitation medicine which conspire against the early application of these principles. The first of these is urgency, and the second is the impaired ability of the patient to exercise autonomy.

Urgency may be a barrier to the application of these principles. However, resuscitation may be initiated and reviewed in the light of enquiries regarding the patient's likely wishes and consideration of the likely outcome of the resuscitation endeavours.

The impaired competence of patients undergoing resuscitation leaves the principle of respect for autonomy on difficult ground as the patient is limited in his or her ability to receive information, comprehend it, consider it in context, and make a rational decision on the basis of his or her consideration. The degree of this impairment will vary with the gravity of the illness or injury. A patient undergoing cardiopulmonary resuscitation (CPR) for example, will be unable to perform any of these tasks, whereas a patient with life-threatening trauma after a road crash may be able to receive information, to comprehend and to respond in a limited capacity. Although this paper has relevance to each of these, the focus will be on the unconscious patient undergoing resuscitation. It is common practice not to seek or to ignore the wishes of the patient and instead to presume that resuscitation is the right thing to do based on arguments of beneficence and non-maleficence. It is generally perceived that consent is not required because resuscitation brings benefit and prevents harm and because the patient is not in a position to give or withhold consent. Although this approach to resuscitation usually does not mean

Hippocrates wrote in his work *Epidemics*: "As to disease, make a habit of two things - to help or at least to do no harm".¹ The primacy of helping

that bad things are done, from an ethical perspective it is fundamentally flawed. Resuscitation can bring about a number of undesired consequences, ranging from the discomforts of the resuscitation procedures to survival with an unacceptable quality of life. I have discussed the harms of resuscitation previously.³ As with any other medical intervention there are benefits and harms to consider and some form of consent must be obtained for resuscitation to proceed.

Consent for resuscitation

Informed consent is appropriate for planned procedures but is usually impossible during resuscitation due to the urgency of the treatment and impaired patient autonomy. Even in the absence of impaired patient competence, urgency in itself is coercive and it limits the time available for adequate informing and deliberation. More often than not patient competence is impaired by hypoxia, hypovolemia, head injury, distracting pain or other distresses, or illicit or therapeutic drugs. However, if informed consent is not relevant, other forms of consent still are. The two most common forms of consent employed in resuscitation scenarios are presumed consent and proxy consent, and occasionally prior consent or refusal may be indicated in an advance directive or a do-not-resuscitate order.

Resuscitators can presume consent on the basis of three possible derivations of that presumption. The first is to presume consent because, based on general professional judgment, the proposed intervention is considered the right thing to do. Alternatively consent may be presumed because a rational and autonomous agent would consent in a hypothetical circumstance of being able to consent to the proposed intervention. The third derivation is to presume consent on the basis of predicting that the individual for whom the resuscitation is proposed would consent if able to (ie if not impaired).

The presumed consent model for resuscitation may be criticised for its inability adequately to embrace the principle of respect for patient autonomy. The third derivation of the presumption attempts to perceive the proposed resuscitation from this particular patient's perspective whereas the previous two, and particularly the first, are paternalistic in their motives to the extent that they are based on the principles of beneficence and non-maleficence with no or little regard for the principle of respect for autonomy.

Joel Feinberg⁴ made a distinction between strong and weak paternalism which he later referred to as hard and soft paternalism. Weak or soft paternalism describes the situation where

autonomy is compromised or impaired and where beneficence and non-maleficence override any autonomous objection to treatment. In most resuscitation interventions the paternalism is of the softest sort as there is no objection to treatment but merely an absence of explicit consent. However, a blanket presumption of consent does tend to give insufficient consideration to the benefit/harm balance of the resuscitation endeavour and to the fact that many would decline consent, under some circumstances of resuscitation, if they had the ability to do so. Hiberman and colleagues, after applying the principles of beneficence, non-maleficence, autonomy and justice to the application of cardiopulmonary resuscitation, conclude that it should be performed when justified by the extensive outcomes literature; not performed when not desired by the patient or not indicated, and performed infrequently when relatively contraindicated.⁵ The outcome literature for cardiopulmonary resuscitation is extensive and has been reviewed.⁶ Attempts have been made to estimate the desire to receive cardiopulmonary resuscitation. Rosenfeld and colleagues found that approximately two thirds of seriously ill patients wanted cardiopulmonary resuscitation in the event of cardiac arrest,⁷ and Bruce-Jones and colleagues found a similar proportion of acute geriatric unit patients desired it, with poorer personal health and social circumstances contributing to preference not to receive CPR.⁸ However, the likelihood of success after CPR may be misrepresented in the public imagination⁹ and the preference for CPR among those better informed may be less. Hauswald and Tanberg¹⁰ surveyed 105 emergency physicians, nurses and medical technicians who regularly resuscitate cardiac arrest victims and asked their presumably well-informed population what they would like done if they were the arrest victim. Sixty-five per cent wanted resuscitation to cease before the second dose of adrenaline and 10% wanted no resuscitation at all. Only three per cent were willing to undertake full resuscitation as currently practised. Similar results were obtained when New Zealand emergency nurses were surveyed (Ardagh M, unpublished). These and other studies¹¹⁻¹³ tell us that some prefer CPR and some do not, and that preferences are influenced by disease severity, life values, social circumstances and a perception of the likely outcome of CPR. However, none allow an accurate prediction of the preferences of an individual undergoing CPR and most emphasise the value of allowing the prior expression of preference in the form of an advance directive.

Proxy consent attempts to honour the principle of respect for autonomy by transferring the patient's

autonomy to a proxy and thereby limiting the possibility of physician-based paternalism. However, I will contend that this does not adequately raise the level of respect for patient autonomy and it may lessen the contributions of beneficence and non-maleficence in the patient's care.

We can break down respect for patient autonomy into two general components: the first is to give the patient information and the environment necessary for adequate deliberation and the second is to respect the preference expressed by the patient on the basis of this deliberation. In a resuscitation scenario, the pressures of urgency mean that a proxy is frequently not given the time nor the environment for adequate deliberation and even if he or she is allowed to sit and deliberate medical staff may be selective in their informing because of constraints of time. When the proxy expresses a preference, obviously the preference is not that of the patient although, ideally it should approximate it. Proxy consent using substituted judgment more reasonably respects the wishes of the patient by asking the proxy to give consent on the basis of what he or she perceives the patient would want rather than what the proxy wants for the patient. However, even if informing and deliberation were ideal and the proxy was able to give a preference based on what he or she perceived would be the patient's wishes, there are two influences which will contribute to distorting this preference. Very rarely proxies may decline resuscitation consent because of some pecuniary advantage to them expected to result from the patient's death. Much more commonly proxies will give consent to resuscitation procedures for fear of contributing to the patient's death by declining resuscitation, no matter how hopeless that resuscitation might be. In order words, proxies will tend to say, "Yes" to resuscitation on occasions when patients would have said "No", because the patients would perceive an unfavourable balance of harm over benefit from their perspective. Furthermore, the process of achieving proxy consent is an unfair burden to place upon the patient's relatives or loved ones. At a time which is already emotionally fraught they are then placed in the situation of making an apparent life and death decision for their relative based on limited information and understanding. There has been no evidence produced that proxy consent is a better respecter of patient autonomy than presumed consent. Instead, it may be a poor reflection of patient autonomy and it may lead to resuscitation decisions which are not rationally based on perceptions of benefit and harm.

Professional substituted judgment

If we are to honour the principles of respect for patient autonomy, beneficence and non-maleficence when starting and continuing resuscitation we must try and achieve the best balance between benefit and harm and try to see this from the patient's perspective as best can be achieved under difficult circumstances. I will argue that the people most appropriately placed to appreciate the benefit/harm balance are the medical resuscitators. The reasons for this are as follows:

1. Information is limited during a resuscitation scenario.
2. The benefit/harm balance is continually changing as more information becomes available and as the patient responds or does not respond to various endeavours
3. Urgency to begin and to continue resuscitation endeavours means that there is not time for adequate informing of others and for others to deliberate to any lengthy extent.
4. The rapidly changing benefit/harm balance described above means that any deliberation that might occur loses relevance as the resuscitation proceeds.
5. The disease or injury leading to the requirement of resuscitation and the patient's response to that disease or injury are unique and therefore outcomes can never be clearly defined for an individual undergoing resuscitation. The best appreciation of the likely outcome comes from the accumulated experience of previous resuscitations and from a knowledge of discussion of outcome issues in the medical literature and other forums.

I will argue also that, although there is no ideal way of viewing this information from the patient's perspective, the best people to view it from the patient's perspective are the medical resuscitators. The reasons for this are as follows:

1. The resuscitators, as described above, have the best grasp of the benefit/harm ratio in general terms and are therefore best armed to attempt to view it from the patient's perspective.
2. The resuscitators are less influenced by the emotive milieu surrounding the patient's illness and are not susceptible to the protective or defensive attitudes which may coerce a proxy into consenting.

The weakness the resuscitators have is that they lack the ability to understand the life and views of the patient. However, if attempts can be made to ascertain these views, with a default to

resuscitation when there is doubt, then the resuscitators will err on the side of keeping the options open until the benefit/harm balance as perceived by the patient is more clearly in focus. The presence of an advance directive or a do-not-resuscitate order gives the resuscitator a valuable insight into the patient's perspective and will aid this process.

The process of consent using substituted judgment by professionals involves the resuscitators gathering as much information about the patient as they possibly can, which would involve speaking with the patient's loved ones, caregivers, bystanders or anyone else who can assist in this process and due consideration of any prior record of the patient's wishes. With their acquired professional knowledge of the likely outcome of the resuscitation based on previous experience and a knowledge of medical literature and with their knowledge of the injury or disease afflicting this patient, and the patient's response so far, the resuscitators can then exercise their moral imagination by imagining themselves as the patient, with the patient's condition and value system, and asking: "Would I want this treatment?" In this way, the patient's autonomy is respected as best it can be under difficult circumstances by combining a knowledge of the harms and benefits of the resuscitation with an appreciation of this balance from the patient's perspective as best it can be defined. If the answer to the question is, "No, I would not" then the resuscitation should not proceed. To resuscitate without regard for the patient's perceived wishes is to show a harmful disrespect for the patient's autonomy. Often, and appropriately, a decision to proceed will be made on the basis of a perceived balance of marginal benefit over harm that is made more appealing by the prospect of an alternative of certain death if resuscitation is not undertaken. Furthermore, the perception of the harm/benefit balance from the patient's perspective may be unclear and under these circumstances it is appropriate to give the patient a trial of treatment. However, the balance is dynamic, with a clearer view of the likely benefits and harms emerging as the patient responds or does not respond to resuscitation endeavours. As soon as the answer to the question becomes, "No I would not want this resuscitation", then the resuscitation, must stop.

The concepts of withholding and withdrawing treatment are somewhat misdirected in that they imply a need for permission to stop the resuscitation whereas the precedent in medicine is to get permission to proceed. It is wrong to withhold a

resuscitation endeavour because of the concern that the lifesaving treatment cannot be withdrawn at a later date if things are not going well. When resuscitation is withheld a small but significant number of patients may miss out on an opportunity for a good outcome had the resuscitation been offered to them. Similarly it is wrong to be unable to withdraw resuscitation because of the ill-conceived concept that once resuscitation has begun it must continue.

By employing professional substituted judgment the resuscitator should recognise when the balance of benefit and harm becomes unfavourable from the patient's perspective and at that point the resuscitators have a moral obligation to withdraw resuscitation as they can no longer presume the patient's consent. In this way the patient's autonomy is resurrected and the principles of beneficence, non-maleficence and respect for patient autonomy are more favourably balanced than under other resuscitation decision making processes.

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