

The Role of Religion and Culture in Clinical Ethics Consultation

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ABSTRACT

This paper discusses the role a patient's religion and culture should play in analysing and discussing ethical issues in clinical ethics consultation in a multi-cultural environment. The first part of the paper presents a case of a family requesting a specific, normally very minor non-clinical procedure to be performed on an elderly patient with severe dementia as part of the preparation for a very significant religious festival. This had been done the two preceding years but staff was now unwilling to perform the procedure because the patient had become agitated when it was performed a year ago. The case was therefore brought to the clinical ethics committee (CEC) which had to consider two issues:

1. Should the procedure be performed by the staff?
2. If not, should staff allow relatives to perform the procedure?

Based on this case the paper will then discuss:

1. Does it matter whether the procedure is required by religion or culture?
 - a. Can a clear distinction be drawn between religion and culture?
2. Does it matter what view the majority culture has on this procedure?
3. Does the patient's own previously held views matter and why?

I will argue that the distinction between religion and culture or between what is required by religion and what is "merely" cultural is in most cases spurious and drawn primarily to either valorise or devalue a certain practice.

What matters is whether a given value is deeply held and whether giving it up will require major transformations in a person's system of beliefs (in the non-religious sense of beliefs). I will further argue that an attempt to determine the patient's objective "best interest" is also futile and unlikely to further the resolution of the problem since that concept is culturally determined.

Introduction

It is generally accepted that when a proxy decision maker makes a decision for an incompetent person that decision has to be made in the best interest of the incompetent person (1). This holds both for family and for professional proxies. From this it follows that when a clinical ethics committee (CEC) is asked to advise in cases involving incompetent patients the CEC should advise the clinicians to follow the course of action that is in the patient's best interest. But deciding whether something is in the best interest of the patient is not always a straightforward matter and it may in some cases be extraordinarily difficult and contentious. In this paper I will discuss a case that illustrates these problems.

Mr. A was an elderly Muslim gentleman with slowly progressing, but now fairly severe dementia. He had been a resident of a nursing home for several years. He could sometimes recognise his family but it was clear to everyone that he no longer had decision making capacity, even in relation to very simple matters. Before he became demented he had always maintained a high degree of adherence to the standards of propriety common in his ethnic and religious community. He was a first generation immigrant but had lived in the country for many years. His religion required that all body hair was removed once a year before one of the most important festivals in the religious calendar. When his body hair had been shaved the previous year he had become agitated and was nicked once by the shaver. His family had asked that this religious preparation could be performed again this year, but the case was brought to the CEC by the staff who wanted support for the decision not to perform the shaving.

What advice should the CEC give?

Substituted judgement as best interest

There is no doubt in this case that if Mr. A had been competent he would have performed the hair removal himself, as he had done every year of his adult life, and that if he had become merely physically unable to do it he would have got someone else, probably one of his sons to do it for him. What role should this fact play in our analysis? If

we think that the appropriate standard for proxy decision making is substituted judgement instead of best interest we might initially be lead to the conclusion that Mr. A's strong and undoubted commitment to this particular course of action should be dispositive of the decision making. Because Mr. A would have pursued this course of action, had he been competent we should now, as his proxies pursue this course of action.

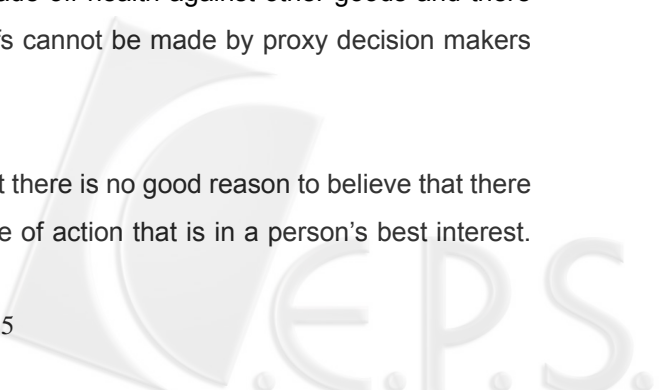
But this is too hasty, because even under a substituted judgement standard the question we have to ask is something like "what would a competent Mr. A decide to do, if he knew that there was a great likelihood that he would not understand what was happening to him and that he would become agitated?" To answer that question we need to know much more about Mr. A and the reasons why he, throughout his life had consistently chosen to adhere to this and other standards of propriety. We also need to know how Mr. A had viewed the various exemptions from religious observance allowed by Islam. Such information might be difficult to come by. It is common that those who are truly devout are also those who feel least compelled to give reasons for their devotion. And if Mr A had never had reason to think about exemptions he might not even have formed a view about them.

Best interest and personal values

Let us now assume that we have decided that the right approach to proxy decision making is not to try to divine what Mr. A would have decided if he could decide, but that the right approach is to try to find out what is in Mr. A's best interest now.

In this context it is first important to note that best interest is not the same as medical best interest, but that best interest properly conceived encompasses a much wider range of considerations. Health is undoubtedly important, but it is not the only thing that is important. Competent people often trade off health against other goods and there are no good arguments why similar trade offs cannot be made by proxy decision makers for the incompetent.

It is also important to keep in mind that there is no good reason to believe that there will always, or even often be only one course of action that is in a person's best interest.



There may be several, or we may be in a situation where we cannot determine what is in the person's best interest. I have argued this point in a previous paper written with Andrew Edgar and will not repeat the argument here (2).

And finally we have to remember that our intuitive response to this case may be influenced by the fact that the request is alien to our culture. Would we have the same intuitions about someone wishing their husbands beard shaved in time for the Christmas dinner? Given these caveats, how should we go about deciding what is in Mr. A's best interest? In the current case the agitation and risk of physical harm counts against the procedure and Mr. A's previous commitment to religion and propriety counts for it.

One way of resolving the problem is to find a way of showing that shaving is not, and has never been in Mr. A's best interest. It is perfectly possible that a competent person is mistaken with regard to what is in his best interest and thus possible that Mr. A and his family have been and are mistaken. Should we not therefore investigate whether there really is a religious obligation to shave before this particular festival?

In Islam there is, at least in principle a clear hierarchy of authority of sources. The Quran is most important, followed by the Hadith (i.e. the accounts of the custom and sayings of the Prophet and his first followers), followed by the consensus of scholars and custom. There is no Quranic authority for shaving of body hair, but there are a few reliable hadith with a good isnad (i.e. provenance or line of transmission) that locate shaving of the pubic hair as part of the Fitra (the good deeds that are not obligatory but highly commended and that are known to all through their conscience). A representative hadith from Bukhari, one of the major hadith collections for instance state that:

"Volume 7, Book 72, Number 778:

Narrated Ibn 'Umar:

Allah's Apostle said, "To shave the pubic hair, to clip the nails and to cut the moustaches short, are characteristics of the Fitra." (3)

We could therefore argue that Mr. A had been mistaken in his belief that a religious obligation existed and/or in his belief concerning the strength of such an obligation. If it is only a "highly commended" action it cannot be obligatory.

But this would, again be too hasty. Religious requirements are not only or perhaps even primarily ABSTRACT obligations derived through correct textual exegesis of holy texts. Religious requirements are embodied in a faith community and most often inextricably intertwined with a much larger cultural tradition. If everyone in the community with which Mr. A identified believes that a specific religious obligation exists, then that obligation exists for them. There may be other Muslims, belonging to other communities for whom this obligation does not exist, but it is a general fallacy, interestingly often shared by fundamentalists and secularists that there is an ABSTRACT and pure Islam we can refer to in order to decide whether Mr. A is really obligated.

And even if we had after careful analysis of Islamic sources decided that there was no Islamic basis for Mr. A's prior practices, that they were purely culturally determined it still would not determine whether we should take into account these practices in deciding what would be in Mr. A's best interest. The fact that I wear clothes that cover most of the body and that certain tribesmen on Papua New Guinea wear nothing apart from penis sheaths is mainly decided by culture. It could, if we discount differences in weather between the UK and Papua New Guinea have been the other way around. But the fact that style of clothing is culturally determined and could have been otherwise says nothing about whether or not it is in someone's best interest to wear a particular style of clothing. If I live in a culture that have strong views concerning proper clothes and I have internalised those views and made them mine, then it is and continues to be in my interest to be dressed in a proper way if I become unable to dress myself.

What matters is not whether a view on a particular set of interest is religious or cultural or purely self-chosen, but whether it is strong, sincerely held and integrated with other parts of the person's personality.

Another question to explore is whether Mr. A's interest in fulfilling his religious / cultural obligations has disappeared because he now has severe dementia? It is tempting to pursue an analysis along the following lines: 1. When Mr. A was competent it was in his interest to fulfill his obligations because of either the psychological or the reputational effects of not following them, but 2. In his present situation Mr. A will not experience any negative psychological effects if he does not discharge his obligations and it is unlikely that there will be any reputational effects (he is in a nursing home and if there is any blame it

may well be apportioned to the nursing home staff and not Mr A), therefore 3. It was previously in Mr. A's interest to discharge his obligations, but it is no longer so.

But this analysis is surely wrong, because it obscures important features of the case. Although not certain it is very likely that if we had asked Mr. A why it was important to discharge this, and similar obligations he would have said that 1. That acting in this way was the right thing to do and 2. That not discharging ones religious obligations had religious consequences. A central tenet in Islam is after all absolute submission to the will of Allah. Mr. A's interests in doing the right thing and submitting to the will of Allah are very plausibly not affected by whether he will experience any negative psychological effects and therefore persist. To use a distinction made by Ronald Dworkin (4), sincerely held religious interests are not experiential but critical and persist even in those with severe dementia. To claim otherwise is tantamount to claiming that Mr. A was, and had always been wrong in believing that he had religious interests.

Other options

In considering this case it is important not to limit the possible courses of action prematurely. In the analysis so far it has been an implicit assumption that the CEC only has two courses of action it can advise; Either the staff shaves Mr. A's body hair or they refuse to do so. But this does not really exhaust the space of possible actions. Hair can be removed in many ways and since it is the end state and not the specific means that were important to Mr. A and are important to his family it might be worth exploring whether there is a form of hair removal that can be used without Mr. A becoming agitated and potentially physically harmed. Could the staff, for instance use an electric shaver or hair removal cream?

Another option would be to allow Mr. A's sons to shave their father. They may be able to get a better rapport with their father and they may conceivably have much more time to spend calming him and convincing him that he will not be hurt.

A third option would be to ask for advice from a respected religious or other leader in Mr. A's community. Most religions and cultures provide explicit or implicit ways of

exempting the incompetent and the infirm from their obligations, or of making it possible to discharge the obligation in a purely symbolic way. Prominent examples in Islam are exemptions from the Ramadan fast for those who are ill and from the prohibition against using pork products for those who need medical products derived from pigs. It may be the first time this specific problem has arisen in the context of a community member in a nursing home, but it is surely not the first time this problem or very similar problems have been encountered by Mr. A's community. Dementia occurs in all cultures. The family may, quite rightly regard the nursing home staff and the CEC as culturally incompetent outsiders but may listen to the advice of a respected insider.

Conclusion

Two related conclusions follow from the analysis above: 1) we are not in a position to say with certainty whether shaving Mr. A is in his best interest and 2) we cannot say with certainty that shaving him is not in his best interest. If Mr. A had not become agitated on a previous occasion it would have been much easier to claim that shaving was in his best interest, because there would have been no countervailing considerations.

From these conclusions it seems to follow that if his family after consultation with community leaders still want the procedure to go ahead we should explore less traumatic ways of removing Mr. A's body hair and that we should at least try to fulfill the requirements of the family and only refuse if Mr. A becomes agitated again.

References

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