Editorial

End-of-life decisions

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Several papers in this issue of the journal and an important, though to some controversial, set of guidelines from the British Medical Association (BMA) warrant a return to the issue of withholding and withdrawing life-prolonging treatment - including artificial nutrition and hydration (ANH) - in contexts where though they may prolong life they are judged incapable or highly unlikely to provide any health benefit to the patient concerned; or, in contexts where the patient has previously and competently refused such treatment. The Greek case described in this issue by Drs Garanis-Papadatos and Katsas tells of an 82-year-old woman in semi coma after a severe cerebrovascular accident (CVA) who in her first six weeks of hospitalisation repeatedly expressed her wish to die both by signs and a few uttered words, and by trying to remove the nasogastric feeding tube. Her children, aware of her lifelong aversion to hospitals asked the doctor about the possibility of withdrawing treatment. He was totally opposed, but after the patient’s further deterioration into complete and irreversible coma the physician agreed to withdraw artificial nutrition while insisting on maintaining intravenous hydration. It was the most fundamental form of care and he as a doctor was obliged to provide it - and his personal stance was supported by both medical and religious tradition. The patient survived two more weeks and died from a further CVA. The authors tell us that this doctor’s views accord with those of the majority of Greek doctors. They also add that were a Greek prisoner undertaking a hunger strike to refuse artificial nutrition and hydration the prisoner’s refusal would be honoured. (In this context the paper by Dr Brockman about hunger strikes by prisoners provides fascinating insights.)

Although they do not specifically address the issue of ANH Dr McHaffie and colleagues report on the considerable variation that exists across Europe in legislation and practice relating to withholding and withdrawal of life-prolonging treatment in the case of neonates who are either highly likely to die whatever treatment is given, or, (the source of more controversy) are likely to have severely impaired lives if they do survive. Among their important if unsurprising findings is that whether or not life-prolonging treatment is to be continued, all the countries studied agreed about the importance of maintaining high-quality compassionate care for the patient. Well is ANH to preserve life as long as possible a caring and compassionate thing to provide, regardless of whether or not any benefit to the patient’s health will result, regardless of the patient’s views or, where these are unclear, regardless of the views of those who know the patient well enough to be able to say what the patient is likely to have thought? The Greek doctor referred to by Drs Garanis-Papadatos and Katsas clearly thought so in relation to artificial hydration, while somewhat inconsistently allowing withdrawal of artificial nutrition.

The BMA guidelines, at one with UK law, are at pains to reject this point of view. Keeping someone alive by ANH is not “basic care” it is medical treatment for patients who one way or another are unable to swallow. Furthermore the primary goal of medicine is not to keep patients alive as long as possible but rather “to benefit the patient by restoring or maintaining the patient’s health as far as possible, maximising benefit and minimising harm”. Usually, but not always, prolonging a patient’s life who would otherwise die is a benefit for that patient. But if treatment, including life-prolonging treatment (LPT), would fail, or ceases, “to give a net benefit to the patient (or if the patient has competently refused the treatment) that goal cannot be realised and the justification for providing the treatment is removed”.

The BMA emphasises that such an approach has nothing to do with euthanasia in the sense of intentionally killing a patient. Instead the intention of such withholding or withdrawing is to refrain from providing treatment that is not benefiting the patient. In this the BMA explicitly accepts that foreseeing the almost inevitable death of the patient if LPT is withheld or withdrawn...
does not entail intending that death. Instead it
involves acceptance (by doctors, relatives and
society more broadly) that we are all mortal and
that in some fatal conditions no treatments -
including ANH - are of any benefit to the patient.
And the BMA also emphasises this does not
involve any judgments about the value of a
patient's life - but does involve judgments about
the value to a patient of a proposed or current
treatment.

Opponents argue that nutrition and hydration,
no matter how they are supplied to a patient, are
never medical "treatments" - they are basic care
and basic rights. The BMA, in line with UK law,
rejects this claim. Some forms of providing food
and water to those who are for some medical rea-
son unable to swallow require medical techniques
and skills for their implementation and/or provi-
sion and are properly classified as medical
treatment. While the offering of food and water is
basic care and should not be denied to those who
can swallow food, for those who can't (or for
whom normal feeding is unpleasant, for example
because of choking) the issue should properly be:
is the provision of ANH appropriate? And the
answer should then properly turn on the question:
will such ANH be beneficial to the patient's
health?

Recognising the emotive and for some conten-
tious nature of decisions to withhold - and
particularly to withdraw - ANH, the BMA guide-
lines recommend additional precautions over and
above those it recommends generally for decisions
to withhold and withdraw LPT. These additional
precautions include formal clinical review by a
senior clinician who has experience of the
condition from which the patient is suffering and
who is not part of the treatment team; careful
recording of the case, to be retained for further
clinical review, and mechanisms for ensuring that
all cases where the patient's wishes were not
known are locally reviewed to check that appropri-
ate procedures and guidelines have been followed.

And for all cases of withholding or withdrawing
LPT - whether or not ANH is involved - the BMA
guidelines recommend careful assessment of each
individual case to ascertain whether the treatment
in question will benefit the patient. In such assess-
ment the patient's own views, preferably contem-
poraneous but when these are not available, previ-
ously established when competent, are preferable.
When these are not available parents' views are
especially relevant for children. For adults who
have previously been competent to make their
own decisions the role of family members and
close friends is seen as providing evidence about
what the patient is likely to have considered to be
beneficial. For those who have never had capacity
to make their own decisions "the primary factor
will be the clinical benefits and burdens of the
treatment" assessed as far as possible from the
patient's point of view (as distinct from the pref-
erences for themselves of the health care team or the
family). "The views of those responsible for the
continuing care of the patient, which would
include those close to the patient, should form an
important part of that assessment".

In assessing whether provision of a LPT would
benefit a patient who is unable to advise the doc-
tors either directly or indirectly, various factors
should be taken into account by the doctors who
are ultimately responsible for making the decision.
These include, so far as can be ascertained: the
patient's own wishes and values; clinical judgment
about the effectiveness of the proposed treatment;
the likelihood of unmanageable pain or suffering;
the level of awareness the patient has of his or her
existence and surroundings as demonstrated for
example by the ability somehow to interact with
others, and the capacity for self-directed action or
the ability to take control of any aspect of his or
her life; the likelihood and extent of anticipated
improvement in the patient's condition if LPT is
provided; the degree of invasiveness of the LPT;
the views of the parents if the patient is a child,
and the views of people close to the patient, espe-
cially close relatives, partners and carers, about
what the patient would consider to be beneficial.

The medical actions described by Drs Garanis-
Papadatos and Katsas would surely be inconsis-
tent with the BMA guidelines. It is difficult for this
writer to understand how they could benefit or
"care for" or be in the interests of the patient.
Should the time come for European guidelines,
which approach should be recommended? Debate
is invited.

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