

Extending Autonomy past the onset of incapacity: legal and attitudinal aspects of advance directives

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The right to refuse treatment

- In *Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649, Lord Donaldson MR stated: -

“An adult patient who ... suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered.”
- Lord Goff stated in *Airedale NHS Trust v Bland* [1993] A.C. 789 at 864:

“Moreover the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it; though in such circumstances especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances which have subsequently occurred ... I wish to add that, in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so. It is simply that the patient has, as he is entitled to do, declined to consent to treatment which might or would have the effect of prolonging his life, and the doctor has, in accordance with his duty, complied with his patient's wishes.”

Aims:

- To outline the primary human rights relevant to anticipatory decision-making
- To consider the law relating to anticipatory decision-making in England, Wales & Northern Ireland, assessing the extent to which it enables an adult with capacity to make binding anticipatory decisions to take effect in the event of incapacity.
- To analyse the impact of healthcare professionals' attitudes towards advance decisions upon the validity and binding nature of those advance decisions.

European Convention on Human Rights: Article 2 – Right to life

- 1 Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
- 2 Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:
 - a in defence of any person from unlawful violence;
 - b in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;
 - c in action lawfully taken for the purpose of quelling a riot or insurrection.

- *Airedale NHS Trust v Bland* [1993] A.C. 789
- *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801
- *Regina (Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department intervening)* [2002] 1 A.C. 800
- *Pretty v UK* (2002) 35 E.H.R.R. 1

European Convention on Human Rights: Article 3 – Prohibition of torture

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

- *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801
- *Regina (Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department intervening)* [2002] 1 A.C. 800
- *Pretty v UK* (2002) 35 E.H.R.R. 1

European Convention on Human Rights: Article 8 – Right to respect for private and family life

- 1 Everyone has the right to respect for his private and family life, his home and his correspondence.
- 2 There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

- *X & Y v Netherlands* (1986) 8 EHRR 235
- *X v Austria* (1980) 18 DR 154
- *Regina (Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department intervening)* [2002] 1 A.C. 800
- *Pretty v UK* (2002) 35 E.H.R.R. 1

For an excellent analysis of the right to refuse medical treatment under the ECHR see:

Elizabeth Wicks “The right to refuse medical treatment under the European Convention on Human Rights” (2001) 9 *Medical Law Review* 17 – 40.

The conflict between the sanctity of life and self-determination

In re T (Adult: Refusal of Treatment) [1993] Fam 95 Lord Donaldson MR recognised, there is:

“A conflict between two interests, that of the patient and that of the society in which he lives. The patient's interest consists of his right to self-determination-his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount. But this merely shifts the problem where the conflict occurs and calls for a very careful examination of whether, and if so the way in which, the individual is exercising that right. **In case of doubt, that doubt falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must do so in clear terms.**” (At 112.)

Recognition of the validity of advance decisions in principle

■ *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129

“The first principle of law which I am satisfied is completely clear, is that in the case of an adult patient of full capacity his refusal to consent to treatment or care must in law be observed. ... An advance indication of the wishes of a patient of full capacity and sound mind are effective. ... It follows that the continuation of invasive ventilation, if it is clearly established that an adult patient of full capacity has withdrawn his consent to it, is not simply not the duty of the doctor but is positively unlawful.” (Per Hughes J at 134 - 6.)

■ **S. 26 Mental Capacity Act 2005: Effect of advance decisions**

(1) If P has made an advance decision which is-

(a) valid, and

(b) applicable to a treatment,

the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.

S. 24 MCA 2005: Advance decisions to refuse treatment: general

- (1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if-
 - (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him,
and
 - (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment,
the specified treatment is not to be carried out or continued.
- (2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms. ...

Cf. *In Re T. (Adult: Refusal of Treatment)* [1993] Fam. 95 Lord Donaldson MR set out a four stage test in respect of anticipatory refusals of consent:-

- 1) The patient must be competent at the time of completing the advance directive;
- 2) Her refusal must not be vitiated by undue influence;
- 3) The refusal must sufficiently informed; and
- 4) the situation that arises must fall within the scope of the advance refusal.
(At 113-4.)

Who can make a valid advance decision?

■ s. 2 MCA 2005: People who lack capacity

- (1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.
- (2) It does not matter whether the impairment or disturbance is permanent or temporary. ...

■ s. 3 MCA 2005: Inability to make decisions

- (1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable-
 - (a) to understand the information relevant to the decision,
 - (b) to retain that information,
 - (c) to use or weigh that information as part of the process of making the decision, or
 - (d) to communicate his decision (whether by talking, using sign language or any other means). ...

■ Cf. the capacity test set out by Thorpe J in *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290 at 292

■ N.B. Presumption of capacity – s.1(2) MCA 2005

Format of advance decisions

- No prescribed format except in the case of a refusal of life-sustaining treatment

S. 25 MCA 2005:

- (5) An advance decision is not applicable to life-sustaining treatment unless-
 - (a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and
 - (b) the decision and statement comply with subsection (6).
- (6) A decision or statement complies with this subsection only if-
 - (a) it is in writing,
 - (b) it is signed by P or by another person in P's presence and by P's direction,
 - (c) the signature is made or acknowledged by P in the presence of a witness, and
 - (d) the witness signs it, or acknowledges his signature, in P's presence.

“There are *no* formal requirements for a valid advance directive: there is no legal requirement as to form. ... An advance directive need not be either in or evidenced by writing. An advance directive may be oral or in writing.

The absence of anything in writing goes only to the practicality of proof. For it may be difficult to establish the existence of a binding oral advance directive given, first, the need for clear and convincing proof founded on convincing and inherently reliable evidence and, secondly, the need to demonstrate that the patient's expressed views represented a firm and settled commitment and not merely an offhand remark or informally expressed reaction to other people's problems.”

(*HE v A Hospital NHS Trust*, AE [2003] EWHC 1017 (Fam), per Munby J. at para.s 33 – 4)

Thus, advance decisions may be given orally if the refusal does not relate to life-sustaining treatment, see discussion in *W Healthcare NHS Trust v H* [2005] 1 WLR 834. For an example of an advance decision communicated by blinking see *Re AK (Medical Treatment: Consent)*

In respect of what can an advance treatment decision be made?

- Advance decisions relate only to treatment refusals and cannot be used to mandate specific treatment which may not be clinically indicated (*R (Burke) v General Medical Council* [2006] QB 273).
- That in specified circumstances a specified treatment should not be carried out or continued. (S.24(1) MCA 2005).

The specificity problem

- The treatment refused and the circumstances in which the refusal should operate must be specified, but layman's terms will suffice for specifying both the treatment and the circumstances (s.24(2) MCA 2005).

- **S. 25 MCA 2005: Validity and applicability of advance decisions**
 - (4) An advance decision is not applicable to the treatment in question if-
 - (a) that treatment is not the treatment specified in the advance decision,
 - (b) any circumstances specified in the advance decision are absent, or
 - (c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

- In *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129 : Hughes J stated:

“The expressions of AK’s decision are recent and are made not on any hypothetical basis but in the fullest possible knowledge of impending reality. I am satisfied that they genuinely represent his considered wishes and should be treated as such. ... Given that his express wishes are clear, the conclusion follows from what I have said that once the conditions which he has stipulated arise it will be unlawful to continue invasive ventilation. That would be the law even if his decision to that effect were unreasonable.”

(At 134 – 136.)

- *Werth v Taylor* □(1991) 190 Mich App 141

Invalidity due to action(s) of the patient

S. 25 MCA Validity and applicability of advance decisions

(2) An advance decision is not valid if P-

(a) has withdrawn the decision at a time when he had capacity to do so,

(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

Cf. Lord Goff's observation in *Bland* that in the case of an anticipatory refusal:

“Especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances which have subsequently occurred.” (At 850.)

HE v A Hospital NHS Trust, AE

[2003] EWHC 1017 (Fam)

“Where, as here, life is at stake, the evidence must be scrutinised with especial care. **The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence.**

In my judgment no less rigorous an evidential approach is required where the inquiry is not as to the initial validity of an advance directive but (as here) the continuing validity and applicability of an advance directive given in what may be the more or less remote past. Indeed, depending upon the time that has elapsed, and any known changes in the patient's circumstances during that time, the question of whether an advance directive admittedly made at some time in the past is still valid and applicable may require especially close, rigorous and anxious scrutiny.

(Munby J at para.s 24 – 5)

“The longer the time which has elapsed since an advance directive was made, and the greater the apparent changes in the patient's circumstances since then, the more doubt there is likely to be as to its continuing validity and applicability. There will be cases in which, as I have said, there will need to be especially close, rigorous and anxious scrutiny. ... Since it is quite clear that the Advance Directive was founded entirely on AE's faith as a Jehovah's Witness — that is made clear beyond argument by the very terms of the Advance Directive itself — it seems to me that it cannot have survived her deliberate, implemented, decision to abandon that faith and to revert to being a Muslim. When the entire substratum has gone, when the very assumption on which the advance directive was based has been destroyed by subsequent events then, as Lord Donaldson put it in *In re T*, “the refusal ceases to be effective”. ... There is simply no clear and convincing proof that the Advance Directive is still valid and applicable. The father's evidence having raised doubts — real doubts, not fanciful doubts or mere speculations — those doubts must be resolved in favour of the preservation of life.”

(*HE v A Hospital NHS Trust*, AE [2003] EWHC 1017 (Fam), per Munby J. at para. 45 - 50)

Indications that an advance decision is no longer operative could include:

“Words said to have been written or spoken by the patient ... [or] some change in circumstances. Thus, it may be alleged that the patient no longer professes the faith which underlay the advance directive; it may be said that the patient executed the advance directive because he was suffering from an illness which has since been cured; it may be said that medical science has now moved on; it may be said that the patient, having since married or had children, now finds himself with more compelling reasons to choose to live even a severely disadvantaged life. ...

Once there is some real reason for doubt, then it is for those who assert the continuing validity and applicability of the advance directive to prove that it is still operative. The burden of proof is on them. And, as I have said, what is required is clear and convincing proof. If there is doubt that doubt falls to be resolved in favour of the preservation of life. So, if there is doubt the advance directive cannot be relied on and the doctor must treat the patient in such way as his best interests require..”

(HE v A Hospital NHS Trust, AE [2003] EWHC 1017 (Fam), per Munby J. at para. 43)

The effect of advance decisions – s. 26 MCA 2005

- (1) If P has made an advance decision which is-
 - (a) valid, and
 - (b) applicable to a treatment,the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.
- (2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.
- (3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.

The effect of advance decisions – s. 26 MCA 2005 (cont.)

- (4) The court may make a declaration as to whether an advance decision-
 - (a) exists;
 - (b) is valid;
 - (c) is applicable to a treatment.

- (5) Nothing in an apparent advance decision stops a person-
 - (a) providing life-sustaining treatment, or
 - (b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.

- 1. A representative survey in community dwelling adults from the general population of Västerbotten in northern Sweden; and
- 2. A survey of Swedish and (East-)German physicians and nurses

Table 2 Responses to questions concerning desire for control (by sex, %)

Question	Extremely or very/Yes	Somewhat or slightly/No	Not/Undecided	χ^2	p
How important is it to have a say in deciding what type of health care you receive?					
Females	89.1	10.4	0.4	22.46	0.0001
Males	73.4	25.7	0.9		
Would you like to discuss hospital treatment and investigation issues with your physician?					
Females	97.0	0.4	2.6	7.45	0.059
Males	91.4	1.7	6.7		

Table 3 Responses to questions regarding concerns (by sex, %)

Question	Extremely/Very	Somewhat/Slightly	None	χ^2	p
Are you concerned that, if you became ill and had to go to hospital, tests and procedures would be done without your knowledge or consent?					
Females	24.3	54.4	21.3	11.50	0.022
Males	14.2	57.3	28.4		
Are you concerned that, if you became ill and had to go to hospital, you would be treated too aggressively?					
Females	10.1	65.1	24.9	11.23	0.024
Males	6.9	57.4	35.7		
Are you concerned that, if you became ill and had to go to hospital, you would not be treated aggressively enough?					
Females	30.8	55.0	14.3	10.60	0.032
Males	22.2	54.7	23.1		

Table 4 Responses concerning treatment preferences (%)

Question	Intensive	Surgery	Limited	Palliative
If you had an acute life threatening reversible illness and were unable to communicate, how would you like to be treated?	81.2	13.8	4.5	0.4
If you had an acute life threatening irreversible illness and were unable to communicate, how would you like to be treated?	29.1	21.4	20.5	29.0

Table 5 Responses concerning use of advance directive (%)

Question	Extremely or very / Yes	Somewhat or slightly /No	Not / Undecided
If unable to communicate, how important would it be to you to have an advance directive indicating the level of care?	78.9	18.4	2.7
Would you want to have your desired level of care documented?	66.3	14.0	19.7

Who should use an advance directive?

users	healthy	chroni- cally ill	acutely ill	everyone	nobody	others
n in %	11,7	6,0	5,3	61,1	12,9	3,0

1st scenario

The patient's daughter, who is his only living relative, is away on vacation. His family physician is at a conference, and his locum is unable to give any further information.

2nd scenario

A note from the family physician indicates that 3 weeks previously the patient and his daughter had requested that in the event of a cardiac arrest, no attempt should be made to resuscitate the patient.

3rd scenario

The patient, his daughter, and the family physician had each chosen the maximum therapeutic effort. The signatures of the patient and his family physician were included. It was stated that in the event of cardiac arrest, no cardiopulmonary resuscitation should be attempted.

Treatment Options Provided in the Questionnaire

Option	Description
Supportive measures only (SUPP)	<ul style="list-style-type: none">• Measures that enhance comfort or minimize pain (e.g., use of morphine)• No intravenous lines• Don't group & cross-match• Don't investigate cause of bleeding
Limited therapeutic effort (LIM)	<ul style="list-style-type: none">• Start intravenous line, cross-match, and transfuse• N/G tube, blood tests, and x-ray exam• Cimetidine or ranitidine intravenous• Don't transfer to intensive care unit (ICU)• Don't operate even if the patient continues to bleed
Maximum effort (MAX)	<ul style="list-style-type: none">• LIM plus the following:<ul style="list-style-type: none">• Emergency gastroscopy if necessary• Emergency surgery if necessary• Don't ventilate (except for surgery)
Maximum effort with ICU (MICU)	<ul style="list-style-type: none">• MAX plus the following:<ul style="list-style-type: none">• Transfer to ICU• Ventilate if necessary• May insert central lines, Swan-Ganz, etc., if necessary

Note. N/G = nasogastric.

Factors of importance in end-of-life treatment decisions in general

- family wishes
- patient wishes
- ethical concerns
- patient's age
- patient's level of dementia
- hospital costs
- legal concerns
- physician's religious beliefs

Table 4 Important factors for decision-making in the elderly by sample and regression on the treatment option by scenario (first line: median/% with answers of extremely and very important; second line: Spearman correlation coefficient first/second/third scenario—significant *R* in bold)

	<i>Swedish physicians</i>	<i>Swedish nurses</i>	<i>German physicians</i>	<i>German nurses</i>
Patient wishes	2/88.5 0.03/0.06/0.06	1/95.9 0.02/−0.03/0.22	2/71.2 0.04/0.05/0.01	2/80.2 0.22*/0.31*/0.31*
Ethical concerns	2/94.2 0.06/0.09/0.09	1/95.1 0.01/0.07/0.01	2/89.0 0.07/0.04/−0.01	2/87.4 0.20*/0.21*/0.23*
Family wishes	3/31.1 0.07/0.04/0.04	2/69.4 0.07/0.14/0.25	4/6.3 0.11/0.17/0.07	4/22.0 −0.12/−0.06/−0.10
Legal concerns	3/39.4 0.15/0.17/0.17	2/68.6 −0.09/−0.05/−0.01	3/39.8 −0.09/−0.02/−0.08	2/53.3 −0.07/0.10/−0.01
Level of dementia	3/42.3 0.51*/0.49*/0.49*	3/21.5 0.36*/0.31*/0.11	4/13.1 0.34*/0.35*/0.33*	4/25.8 0.45*/0.39*/0.37*
Patient's age	3/56.7 0.17/0.19/0.19	4/6.6 0.19/0.08/0.24	4/13.6 0.18/0.19*/0.16	4/20.3 0.44*/0.40*/0.38*
Religious beliefs	5/11.5 0.07/0.02/0.02	5/15.6 0.16/0.16/0.01	5/17.4 0.02/0.09/0.09	5/7.1 0.07/−0.05/0.03
Hospital costs	5/7.7 0.24/0.19/0.19	5/9.9 0.12/0.04/0.01	5/2.6 0.07/0.09/0.17	5/3.8 0.03/0.10/−0.01

Median: 1 = extremely; 2 = very; 3 = moderately; 4 = somewhat important; 5 = unimportant; **p* < 0.01 for *R*.

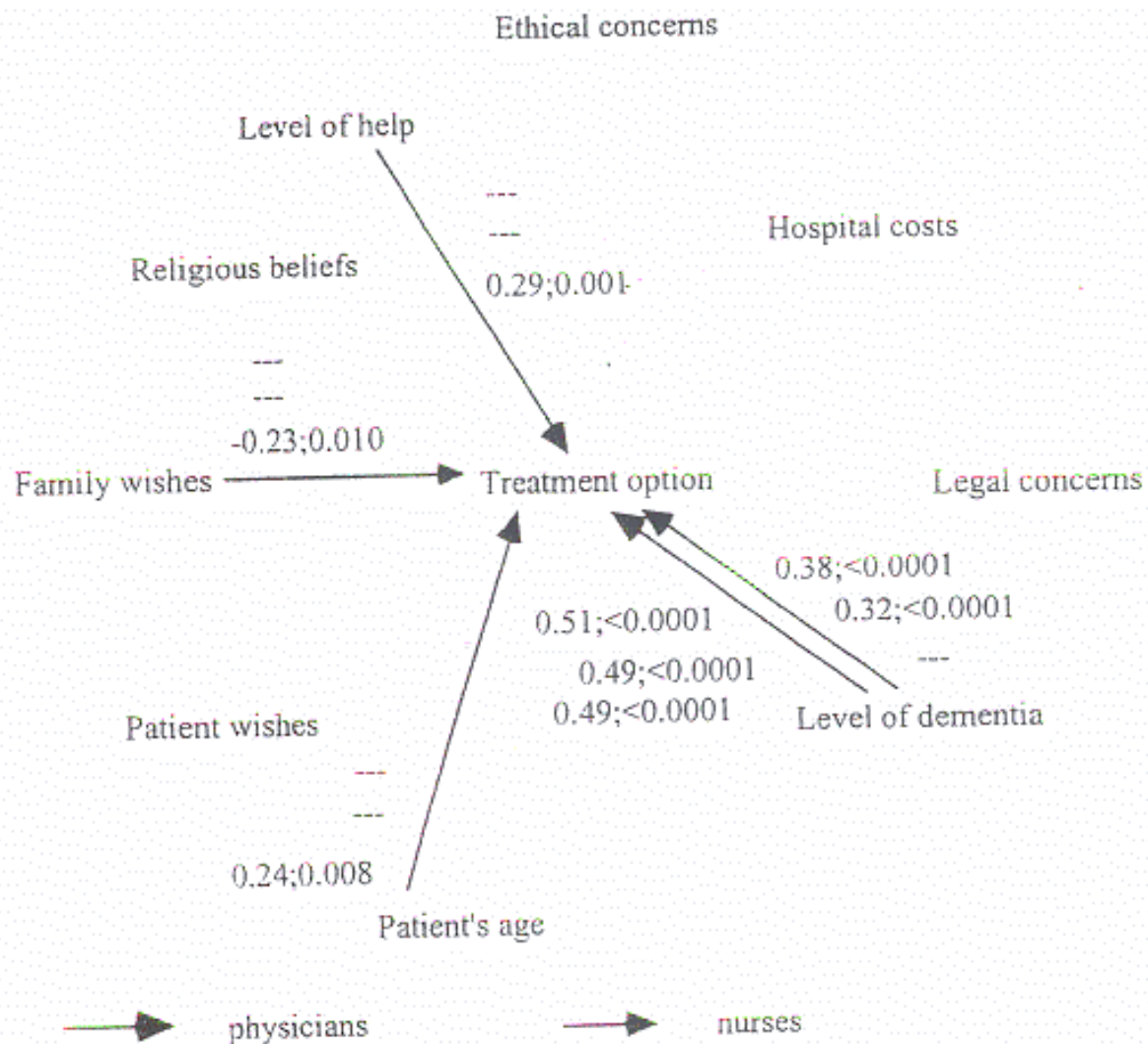


Fig.1 Relationships with treatment options for the Swedish groups (first line – first scenario; second line – second scenario; third line – third scenario)

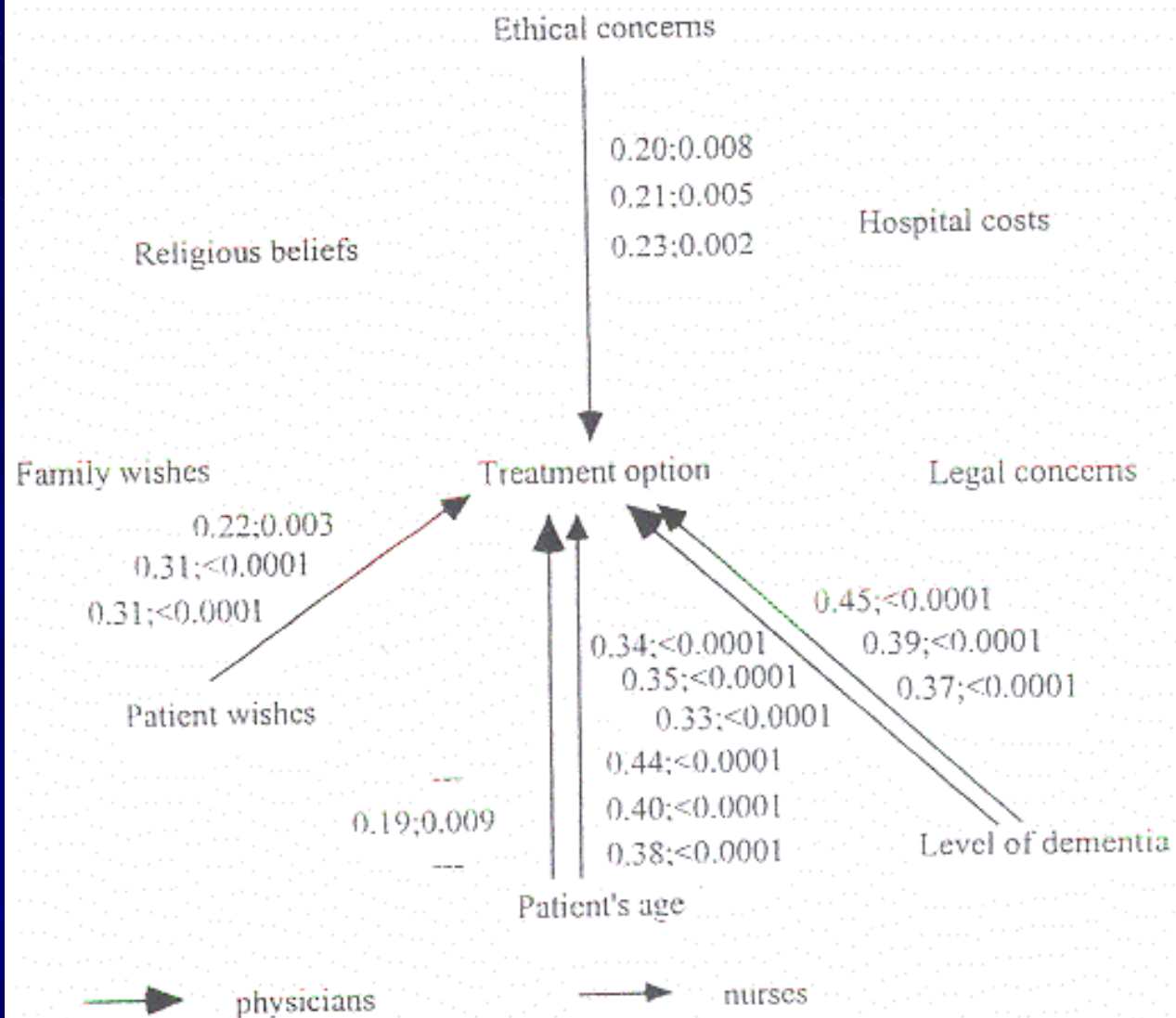


Fig.2 Relationships with treatment option for the German groups (first line – first scenario; second line – second scenario; third line – third scenario)

Measures needed to implement Advance Directives

- Legal recognition of advance directives
- Education of the public about their rights to self-determination in health care and encouragement of individuals to use advance directives
- The willingness on the part of health care professionals to educate patients about advance directives and to provide a reasonable amount of time to discuss this topic by health care authorities
- Routine discussions between family doctors and their patients about health care planning and the use of advance directives.
- The provision of resources to educate professionals and the general public about this issue.

This study indicates that:

- A relatively large number of doctors would not act according the explicit wishes of a patient.
- Nurses showed a stronger tendency to comply with the patient wishes than doctors.
- The more information about patient's wishes that was available, the less CPR attempts were made.
- About 40 % of doctors reported that the advance directive was helpful in decision-making.

- *The most important findings are that*
- DNR orders and, to a greater extent, ADs seem to represent a feasible way to preserve patient autonomy concerning the attitudes of health care providers from the various countries.
- **Most people are highly interested in exercising autonomy in health care issues, including the right to decide how and when to die.**

European Convention on Human Rights and Biomedicine, 1997: Art. 9 – Previously expressed wishes

The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.