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Health professionals' views on advance directives: a qualitative interdisciplinary study

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Abstract: The aim of this study was to discover the views of health professionals in the Greater Glasgow area on advance directives, using semi-structured interviews and focus groups. The twelve participants interviewed included four hospital doctors, four general practitioners (GPs) and four nurses. The six focus groups comprised hospice nurses, GPs, consultant geriatricians, geriatricians in training grades and an interdisciplinary group. Participants were purposively selected to reflect a range of personal experiences with, and attitudes toward, the advance directive using key informants and a short questionnaire. Participants were asked to comment on a specially constructed sample advance directive. All research encounters were recorded, transcribed and analysed using accepted methods in qualitative research. The advance directive was seen as a means of promoting peace of mind in will makers, of allowing carers to honour the patients' wishes and of stimulating communication between all parties. Conversely the advance directive was seen as generating certain risks for the will maker – including those of coercion, misunderstanding, paradoxical overintervention and inadvertent undertreating. A core concern surrounded the issue of 'informedness' in will makers and the ethics of deciding for a future demented self. *Palliative Medicine* 2003; **17:** 403–409

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Introduction

Health care professionals are increasingly prompted to promote patient dignity and autonomy – particularly in the fields of palliative care[1] and care of elderly.[2] These issues are particularly reflected in the decisions that surround the withholding and withdrawing of life-prolonging treatment in the critically and terminally ill – especially those patients who are cognitively impaired.[3] With the usual avenues for discussion closed, professionals are often obliged to exercise 'soft' paternalism[4] – making decisions in the best interests of the incapacitated patient. However, in some situations, there may be access to previously expressed treatment preferences – verbally conveyed by a third party or through the presence of an advance directive (AD).[5]

ADs have been championed by some as a means of preserving both dignity and autonomy in the face of an increasingly 'technophilic' medical system.[6] With an estimated 2% of the UK population having made ADs[7] they remain uncommon but not rare. Though prevalent in younger adults with conditions such as HIV[8] and MS, in demographic terms it is likely to be with regard to cancer, dementia and stroke illness that ADs are mostly commonly applied[9] – conditions where issues of dignity are particularly prevalent.

Despite rich debate on the ethics of ADs there is little empirical data on their use. In particular little is known about the views of health professionals on the practical utility of ADs in protecting autonomy and improving care. Only one such study from the UK has been identified, dealing exclusively with GPs and published as a brief report.[10]

What can health professionals teach us about the merits of ADs in improving care? This is the aim of the research presented in this paper, which employs qualitative methods to explore this question from an interdisciplinary perspective.

Methods

Data was generated through a combination of individual interviews and focus groups. Interviews permitted an indepth study of individual reasoning and the inclusion of those with particularly strong views who might have exercised undue influence in group discussions. Focus groups allowed us to observe how opinions were constructed between group members in a forum that approximated to that of the clinical team.[11]

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The dimensions of the sample included a) professional role, b) experience with AD implementation and c) attitude towards ADs. Different professional groups engage with patients with ADs in different ways – for example nurses are more likely to assume the role of patient advocate[12] with doctors more often in the role of decision maker. The work of Davidson[13] shows that doctors with experience of AD implementation have a more positive view of them than do those with no such prior experience. It was also essential to sample a broad range of opinion and to include individuals who were unusual in occupying an extreme position on the attitudinal spectrum.[14]

The prospectively defined sample quota was met through a variety of methods all well established in qualitative research. Inquiries through 'key informants' led to the identification of relevant members of different professional groups. This method was combined with the use of a short questionnaire, sent for instance to all consultant geriatricians working in the Greater Glasgow area, and allowing the creation of a basic sampling frame. CME and PGEA approval was gained and certificates of attendance were issued. Twelve participants were interviewed: four hospital doctors, four general practitioners (GPs) and four nurses. The six focus groups comprised hospital nurses (in care of the elderly and general medicine), hospice staff, GPs, consultant geriatricians, geriatricians in training grades and an interdisciplinary group (34 persons in total). Annotated details of participants are included in Tables 1 and 2.

At the time that this data was generated (Spring 2000) formal ethical approval was not required as the study did not involve patients. All research encounters were structured around a topic guide created on the basis of pilot work and a literature review. This included a specially constructed sample AD, belonging to a fictitious patient called 'Bella' and produced by content analysis[15] of ADs from the Voluntary Euthanasia Society of Scotland, the Terence Higgins Trust and Robertson published in the *British Medical Journal*.[9] This sample AD is included as Figure 1. Our intention was to create a broad, inclusive, document that would address more issues than any of the individual constituent documents. The sample AD was informally appraised by colleagues for face validity prior to data generation. All participants were supplied with this sample AD, given about two minutes to study it, and then asked for their comments on its strengths and weaknesses. Following this general discussion there were questions on its specific components.

Interviews lasted one hour and focus groups 90 minutes on average. All research encounters were recorded and transcribed verbatim and analysed according to a modified grounded theory approach. This entailed coding of all data for both literal and interpretative meaning with the synthesis of these concepts into the broader themes presented in the findings section.[16] Some coding categories were derived from the topic guide but most were 'emergent'. Most of the coding was done by TT but RB and LS independently coded the transcripts of one focus group and one interview and our various interpretations compared and contrasted from these different perspectives (of clinician, sociologist and ethicist). Analysis was assisted by the use of Atlas.ti qualitative data management software.[17]

Results

Before focusing on the issues raised by the particular wording of the sample AD, participants engaged in a wideranging and general discussion on the relative merits of ADs. The main emergent themes are grouped under the following five paragraph headings. With quotations, the (substituted) names are given (for reference to Tables 1 and 2) along with the participant's work role and the research context ('i/v' for interviews and 'FG' for focus groups).

AD as a means of honouring the wishes of the patient

In nine of 12 interviews, and in all the focus groups, participants acknowledged the role of the AD in safeguarding autonomy when individuals are no longer able to communicate:

> ...it allows her to take responsibility for her own values...and for some people death isn't the worse thing so it allows her to say that 'this is my value judgement', albeit at one point in time but 'these things for me are worse than dying' and that's on record. [Shona: palliative physician – 'mixed' FG]

The ability of the AD to confer peace of mind was brought up in seven of 12 interviews and all the focus groups. All those who did not mention this idea were doctors and this included the three participants who expressed a 'negative' view of living wills in their questionnaire responses:

> I think that the patient, herself, may well have some peace of mind that she's not going to be put in a position which clearly she would find humiliating... people that make documents like this, to my mind, want to make the manner of their dying in harmony with the manner of their living. [Brian: GP – i/v].

It is not only the patient who can gain peace of mind from the AD – at the stage of implementation it can be reassuring to the relatives to know that the wishes of the loved one are being respected and they can have a role in ensuring that this is the case:

Table 1 Focus group participants

Name[a]	Age	Job	Attitude to ADs	Contact with ADs[b]	Legal risk[c]	Own AD?
Nurses Focus Group (all nurses on staff of teaching hospital)[d]						
Bianca	41–50	Ward manager	Positive	No	Yes	No
Laura	21–30	S/N (DOME)	Neutral	No	No	No
Steph	31–40	Palliative Care	Neutral	Yes (1)	No	No
Issy	41–50	Specialist Sister[e]	Positive	N/A	No	No
Janice	31–40	S/N (DOME)	Neutral	No	N/A	No
Annette	41–50	Ward manager	Positive	No	No	No
General Practitioners Group						
Anton	31–40	GP	Neutral	Yes (2)	Yes	No
Ben	41–50	GP	Neutral	Yes (1)	No	No
Cara	41–50	GP	Positive	No	Yes	Yes
Colin	51–60	GP	Neutral	Yes (2)	No	No
Consultants Group (Medicine for the Elderly)						
Gordon	41–50	Geriatrician	Negative	No	No	No
Chloe	31–40	Geriatrician	Neutral	No	Yes	No
Joseph	51–60	Geriatrician	Negative	Yes (2)	No	No
Sunil	41–50	Geriatrician	Positive	No	Yes	No
Hospice Group						
Rupert	31–40	Charge Nurse	Positive	No	Yes	No
Vincent	51–60	Nurse Manager	Neutral	No	No	No
Teresa	41–50	Social Worker	Positive	No	Yes	No
Vera	31–40	Staff Nurse	Neutral	Yes (1)	Yes	No
Multidisciplinary Group						
John	41–50	Manager (PNH)	Positive	No	Yes	No
Flo	41–50	Nurse manager	Positive	Yes (2)	No	No
Jade	41–50	Nurse manager	Positive	No	No	No
Amber	31–40	Geriatrician	Negative	No	Yes	No
Mena	41–50	GP	Positive	Yes (2)	Yes	No
Janet	41–50	Manager (PNH)	Positive	Yes (2)	N/A	No
Noel	31–40	GP	Neutral	Yes (2)	Yes	No
Jody	31–40	Manager (PNH)	Neutral	No	Yes	No
Shona	41–50	Consult': hospice	Positive	Yes (n/a)	No	No
Specialist Registrars Group (SpR) (Medicine for the Elderly)						
Joy	21–30	SPR	Positive	No	Yes	No
Paula	21–30	SPR	Neutral	No	Yes	No
Peggy	31–40	SPR	Positive	No	No	No
Cressy	31–40	SPR	Neutral	No	No	No
Sandy	31–40	SPR	Positive	No	No	No
Marcus	21–30	SPR	Neutral	No	Yes	No
Diana	31–40	SPR	Neutral	No	N/A	No

[a] All names are pseudonyms
[b] If yes the number of occasions is given in brackets
[c] 'Yes' or 'No' in this column refers to concern about the risk of prosecution for not following the terms of the AD
[d] DOME – Department of Medicine for the Elderly
[e] Sister in a unit which deals with young people with severe and life-shortening chronic illness – including HIV and Hepatitis

> I think for the relatives if they, if they're in agreement it can be comforting that they know they're carrying out, they're fulfilling, the wishes of their beloved. [Fenella: palliative physician – i/v].

The phrase here 'if they're in agreement' is crucial. If the relatives are not in agreement the AD may be a means of ensuring the patient's wishes are fulfilled in the face of conflicting pressures.

ADs, relatives and the 'can't let go' scenario

Relatives may have difficulty 'letting go' of loved ones without particular regard for quality of life. A geriatrics Specialist Registrar (SpR) relates her experience with this type of scenario:

> I've seen patients have PEG tubes put in on the basis of a family who have been absolutely convinced, despite all the multi-disciplinary team saying that they don't think that the patient's responsive, that

Table 2 Interview participants

Name[a]	Age	Job	Attitude to ADs	Contact with ADs[b]	Legal Risk[c]	Own AD?
Brian	51–60	GP	Positive	No	Yes	No
Peter	41–50	Surgeon	Neutral	No	No	No
Anita	41–50	GP	?Neg[d]	Yes (2)	No	No
Jeremy	> 60	Geriatrician (retd)	Negative	Yes (2)	No	No
Heidi	41–50	GP	Positive	Yes (10)	No	No
Nigel	41–50	Anaesthetist	Positive	No	Yes	No
Susie	> 60	GP (retd)	Positive	Yes	No	Yes
Imogen	31–40	Nurse: PNH	Positive	No	No	Yes
Jose	31–40	Nurse: hospice	Positive	Yes (6)	Yes	Yes
Gary	31–40	Nurse: CPN	No opinion	No	No	No
Fenella	41–50	Consultant: hospice	Negative	Yes (2)	Yes	No
Viv	41–50	Nurse: geriatrics	Positive	Yes (10)	No	Yes

[a] All names are pseudonyms.
[b] If yes the number of occasions is given in brackets.
[c] 'Yes' or 'No' in this column refers to concern about the risk of prosecution for not following the terms of the AD.
[d] Anita left this box blank but was recruited to the study due to her having spoken vociferously against AD at a postgraduate meeting.

> they are going to get any better, all the rest of it. [Paula: doctor (SpR) – 'SpR' FG]:

Those who champion dignity and autonomy might find this account alarming. Could an AD prevent this sort of scenario? Here is the view of an experienced geriatrician who declared himself negative about ADs in the questionnaire:

> …sometimes a living will can be helpful to us. Occasionally one has a circumstance where we have felt that the patient's life span has come to an end and their quality of life is extremely poor and normally we would not do anything else. We can then be put under pressure by relatives, who often have unrealistic expectations and usually by talking one can solve the problem but funnily enough if the person had a living will it might solve it, quite simply. [Joseph: geriatrician – 'consultants' FG]

The issue of 'informedness' in will making

Health professional concerns over the issue of 'informedness' were common to five of the focus group discussions and all but one of the interviews. These concerns were of two main types. The first concerned misconceptions over the nature (especially the prognosis) of underlying chronic conditions:

> I think lay people sort of tend to bung everything together, you know, they think that if they'd had a head injury they were bound to be a bit bonkers afterwards even if they recovered consciousness. [Susie: GP (retd) – i/v]

The second concern is the failure of will makers to understand the role of certain types of intervention in the effective palliation of distressing symptoms. One nurse was able to draw on her own experience of someone refusing all treatment in a hospice setting 'in complete ignorance of modern treatments and pain control'.

Deciding for a future self

There was a widespread view that the preferences of the well might not equate with those of the unwell and many anecdotes were offered including this from a palliative physician:

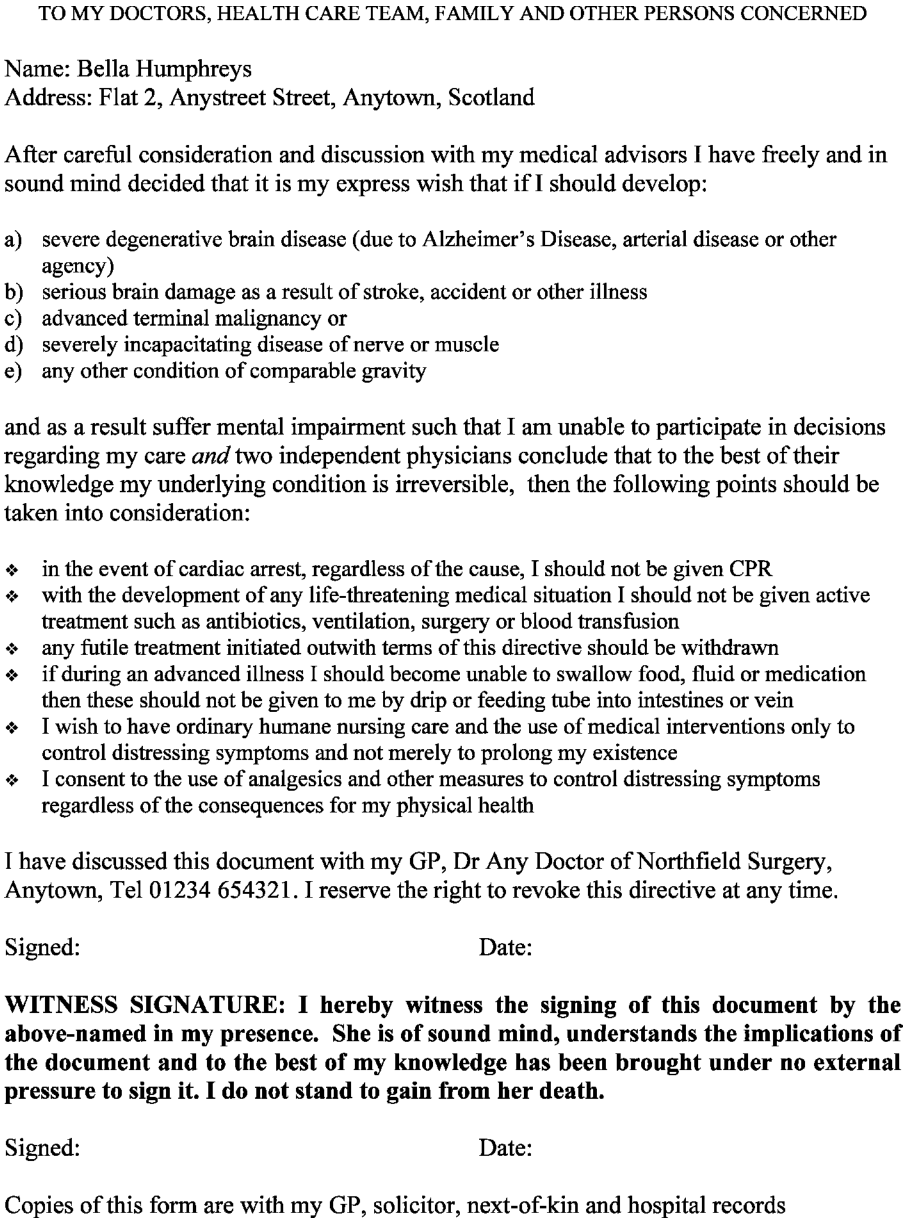
> We've had situations where we've discussed PEG tube feeding with MND patients by showing them videos and a particular patient was adamant he didn't want it – until he was completely unable to swallow then he decided he did want it. [Fenalla: palliative physician – i/v].

This problem is mitigated in situations of irreversible mental incapacity. When carers *have* to make choices it is better that these are informed by written patient preferences – even if these are potentially inaccurate. The alternative is to not have the patient's view incorporated at all – and surrogate decision makers tend to err towards greater intervention.[18] This was the conclusion of one Specialist Registrar:

> if you have a person who you know is not going to be able to communicate anything to you now, they have severe senile dementia that's not going to get better so you can't discuss issues with them, and you know this is what they felt when they were able to make a decision, surely that is valid. [Peggy: doctor (SpR) – 'SpR' FG]

AD as an agent of communication

The presence of an AD in any clinical situation will induce discussion. As one nurse puts it:



TO MY DOCTORS, HEALTH CARE TEAM, FAMILY AND OTHER PERSONS CONCERNED

Name: Bella Humphreys
Address: Flat 2, Anystreet Street, Anytown, Scotland

After careful consideration and discussion with my medical advisors I have freely and in sound mind decided that it is my express wish that if I should develop:

a) severe degenerative brain disease (due to Alzheimer's Disease, arterial disease or other agency)
b) serious brain damage as a result of stroke, accident or other illness
c) advanced terminal malignancy or
d) severely incapacitating disease of nerve or muscle
e) any other condition of comparable gravity

and as a result suffer mental impairment such that I am unable to participate in decisions regarding my care *and* two independent physicians conclude that to the best of their knowledge my underlying condition is irreversible, then the following points should be taken into consideration:

- in the event of cardiac arrest, regardless of the cause, I should not be given CPR
- with the development of any life-threatening medical situation I should not be given active treatment such as antibiotics, ventilation, surgery or blood transfusion
- any futile treatment initiated outwith terms of this directive should be withdrawn
- if during an advanced illness I should become unable to swallow food, fluid or medication then these should not be given to me by drip or feeding tube into intestines or vein
- I wish to have ordinary humane nursing care and the use of medical interventions only to control distressing symptoms and not merely to prolong my existence
- I consent to the use of analgesics and other measures to control distressing symptoms regardless of the consequences for my physical health

I have discussed this document with my GP, Dr Any Doctor of Northfield Surgery, Anytown, Tel 01234 654321. I reserve the right to revoke this directive at any time.

Signed: Date:

WITNESS SIGNATURE: I hereby witness the signing of this document by the above-named in my presence. She is of sound mind, understands the implications of the document and to the best of my knowledge has been brought under no external pressure to sign it. I do not stand to gain from her death.

Signed: Date:

Copies of this form are with my GP, solicitor, next-of-kin and hospital records

Figure 1 Sample advanced directive

> ...the main advantage of an advance directive is as a tool for communication between the medical staff, the rest of the multi-disciplinary team, the patient and the patient's loved ones... [Jose: nurse (hospice) – i/v]

Such communication can begin at the stage at which the AD is being drawn up when the professional carer can help the patient understand its implications. Jeremy, the retired geriatrician, talks about the need to go through the AD and to discover the concerns that underlie each part of it, concluding that:

> The result of that discussion is often that a better rapport is established and that the...the person has a greater trust and a greater willingness to take the particular doctor's opinion. [Jeremy: geriatrician (retd) – i/v].

An additional reason why ADs are so useful in this context is that they trigger conversations on end-of-life issues that professionals can find difficult to initiate:

> it's difficult to broach the subject with a patient whereas someone coming to you with clearly having thought about it, having views on these topics, it's a point from which you can start discussion. [Steph: nurse (pallcare) – 'nurse' FG]

As well as communication between patients and their professional carers the AD can provide a focus for discussions between health professionals and relatives and also within families.

Views on specific components of AD

Following on from this general discussion, participants studied the individual components of the sample AD (presented in Figure 1). The list of persons to whom the AD was addressed (and lodged) and the statement that the document had been discussed with the GP were all viewed by respondents as positive components. That the AD has been discussed with a health professional adds gravitas and was thought to increase the chances of the will maker understanding the implications of what they are signing.

Several participants expressed concern that a depressed person might sign an AD 'almost like a suicide pact' [Gary: nurse (CPN) – i/v]. The issue of coercion in the creation of an AD was a particular worry:

> I have reservations about them because I feel it is very difficult to be sure that the patient didn't agree to it under duress from relatives. [Amber: geriatrician – 'mixed' FG].

The sample AD includes a listing of background conditions and opinion was divided on the necessity for this. For some respondents, as the focus is on irreversible incapacity, then the aetiology is of secondary importance. However the geriatricians' focus group saw it as essential to understand the diagnosis in order to be certain about the prognosis.

For this particular AD to be activated the underlying condition *has* to be irreversible. The recognition of this fact is crucial to its safe implementation. However, several professionals misinterpreted this part of the sample AD – complaining for instance that it meant they could not transfuse a (previously cognitively sound) patient rendered unconscious after a major haematemesis.

This leads to the 'two docs' issue – the conclusion of irreversibility in the underlying condition by two independent physicians. This ostensibly sensible inclusion threw up several issues for the participants including the practical difficulty of obtaining two such doctors especially if 'independent' means unconnected clinically with the case.

The individual bulleted points in the AD were not explored indepth. One nurse said he had particular difficulty concerning the *withdrawal* of interventions and another nurse felt the fourth bullet point might lead to the exclusion of syringe-driver medication despite consent to 'secondary effect' interventions.

In four interviews and all the focus groups concern was expressed that there was nothing in the document about how often it would be updated. This connects to the question of the stability of people's choices – though empirical evidence suggests that they are stable.[19] One suggestion was that the AD should have an expiry date on it forcing the will maker to make formal updates.

The final aspect to be considered in this section relates to the witness statement. Who is the witness – what is her/his relationship to the will maker and on what grounds is s/he able to determine that the will maker is in sound mind?

Discussion

Though the sample is small and from a particular geographical region of the UK, the sampling frame and indepth approach gives us access to a broad scope of opinion. Previous studies have asked participants to comment generally[20] whereas here views are focused on a specially constructed AD. The findings in this study cannot necessarily be generalised to other ADs with different wording. In keeping with survey data,[13] most of the participants acknowledged their strengths and thought them effective agents of autonomy; means by which the person can gain peace of mind and 'make the manner of their dying in harmony with the manner of their living'.

Relatives can also benefit from seeing that the will of the loved-one is being respected. However the AD can also *protect* the individual from relatives, whose need to keep the loved one alive 'at all costs' was cited as a significant driver for overintervention. The AD was seen as a useful stimulus for discussion between family members, professionals and across the lay–professional divide.

Conversely professionals were in agreement that it is very difficult to be fully informed about the sorts of health problems one will have in the future and the implications of various interventions and their refusal. Such misunderstandings are one of several risks that are associated with the use of ADs. For instance, unwise decisions may be made due to cognitive impairment or other mental health problems at the time of drafting the AD or a person could change their mind without getting round to changing their AD. There is also the risk of coercion of the will maker by relatives and other carers.

At the time of implementation there is the further risk that the wording of the AD will be misinterpreted. There are also the risks associated with the appearance of a quasi-legal document in a clinical situation. Clinicians may be uncertain what to do and this can cause delays – for instance in the finding of a second opinion – at a time when swift decisions are crucial. There is also the risk that the AD puts care into the spotlight and removes from clinicians the sort of discretion that might have allowed someone to 'slip away' with dignity. This could, paradoxically, lead to overintervention. Nonintervention does not necessarily equate with better outcome. An untreated patient may survive in a much worse state than they were in prior to the acute illness.[21]

Critical care decisions are difficult decisions. The AD serves to enlighten them with the wishes of the patient made at a time when they were of sound mind. As such the AD should be accorded significant respect as an agent capable of conferring both autonomy and dignity. However, given the sheer complexity of these situations, and the ambiguities of the AD, this respect must be judiciously conferred. Physicians should participate where possible in the drafting of ADs, understanding the values that underpin them, and advising on the import of the various clauses. When it comes to implementation, the AD should not be taken 'as read' but rather understood in a wider context and with awareness of the potential pitfalls discovered in the course of this study. Only then will the AD exemplify the best in 'partnership' decision making.[22] These findings are of particular relevance to practitioners, lay groups promoting ADs, those devising hospital and hospice policy on ADs and as stimulus material in educational interventions aimed at unpacking the implications of these documents.

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