



From Ovid to COVID: The metamorphosis of Advanced Decisions to Refuse Treatment into a safeguarding issue

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From Ovid to COVID: The metamorphosis of Advanced Decisions to Refuse Treatment into a safeguarding issue

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Abstract

Purpose

This paper aims to examine Advance Decisions to Refuse Treatment (ADRTs) in the context of the COVID-19 pandemic. We consider the development of ADRTs, the lack of take up and confusion among the general public, clinicians and health and social care staff.

Design/methodology/approach

The paper is a conceptual piece that reflects on ADRTs in the particular context of COVID-19. It considers professional concerns and pronouncements on ADRTs.

Findings

ADRTs have a low take up currently. There is misunderstanding among public and professionals. There is a need for raising awareness, developing practice and a need to allay fears of misuse and abuse of ADRTs in clinical, health and social care settings.

Originality

This paper is original in considering ADRTs as a safeguarding issue from two perspectives: that of the person making the ADRT and being confident in respect for the decisions made, and of clinicians and other professionals being reflexively aware of the need to accept advance decisions and not acting according to unconscious biases in times of crisis.

Practical implications

We make recommendations that reflexive training and awareness becomes the norm in health and social care, that reform of ADRTs is undertaken to prevent misunderstandings and that the person becomes central in all decision-making processes.

Keywords

COVID-19, ADRTs, 'Do Not Resuscitate' notices, marginalised groups

Introduction

When COVID-19 began to take hold in the UK and people became seriously ill, concerns increased regarding the National Health Service's (NHS) capacity to manage the anticipated rise in demands. Alarm was raised that older people, people with disabilities and those with pre-existing conditions or weakened by ill-health might automatically be assigned 'Do Not Resuscitate' or 'Do Not Attempt CPR'

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3 (DNACPR) notices. Anxieties were also expressed about Advance Decisions to
4 Refuse Treatment (ADRTs), reflecting misunderstandings about their nature and
5 function.
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8 The ramifications of such a battlefield triage mentality were recognised and media
9 reports circulated concerning the active discrimination underpinning this whilst
10 recognising that choice through advance directives might have much to offer in this
11 situation. The unspoken discourses underpinning these fears reveal a safeguarding
12 issue that permeates society and health and social care services and constructs taken-
13 for-granted assumptions of best practice and best interests (see Bourdieu, 1977;
14 Parker, forthcoming). As well as misunderstandings, the lack of take-up of ADRTs
15 reflects anxieties about power being wrested from the self by others within families or
16 by over-stretched clinicians. Moreover, a lack of respect for ADRTs by health
17 professionals demonstrates a social appropriation of safeguarding from the person to
18 the professional expert, which also needs to be addressed.
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22 When we examine the demography of people who have died from COVID-19, it
23 reflects some of the unconscious thinking that denotes an adult safeguarding issue at a
24 macro level. The numbers of older people, people with pre-existing conditions and
25 disabilities, people from BAME communities and working-class people who have
26 died are disproportionately represented when compared with other groups in society.
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29 The terrible nature and effects of radical intervention and intubation and the enduring
30 effects of COVID-19 infection post-ICU for those who survive have led some to
31 conclude that perhaps people would rather have died. This has led to unethical actions
32 in suggesting that treatment should be unequally provided, again raising safeguarding
33 needs. Questions of decisions to withhold treatment for pragmatic reasons have the
34 potential to affect the making of an advanced decision to refuse treatment (ADRT).
35 The fear being that such a decision may be more readily assumed when there is still
36 the possibility of effective curative treatments or when clinicians are stretched and
37 faced with rationing treatments, or the ADRT addresses a different situation to that
38 specified within it.
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42 In the context of adult safeguarding, this paper considers the development of ADRTs
43 and their potential to assist both clinicians and people with COVID-19, adding a
44 moral perspective to treatment decisions in the light of our current knowledge of
45 COVID-19. It moves us from a potentially abusive situation of scant regard for those
46 deemed 'vulnerable' because of certain characteristics – age, pre-existing health
47 condition, intellectual or cognitive disability and so on – to a changed state in which
48 expressed wishes can be transparently shared across family members and health care
49 professionals (hence the metamorphosis implied in the title.) Thus ADRTs can disrupt
50 the tendency towards convergence around assumed wants and wishes to personal and
51 diverse decisions based on prior stated wishes (Beckert, 2010).
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54 **COVID-19 and defining adult abuse**

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56 When we think of adult safeguarding, conscious reasoning suggests to us notions of
57 physical, psychological, financial, sexual abuse, and neglect (Penhale and Parker,
58 2020). Whilst *No Secrets* (Department of Health, 2000) included reference to
59 discriminatory abuse, this and the allied concept of structural abuse has been little
60 considered. The Care Act 2014 has consolidated definitions of abuse and its breadth is

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3 helpful when considering safeguarding in a time of COVID. If it is the in-grained
4 concept of our evaluations of the 'other' and differences in society that creates the
5 conditions for adult abuse to occur, we have an imperative to identify and address
6 underlying the socio-structural aspects of abuse, including those which permeate
7 popular and clinical understandings of ADRTs and associated directives. The
8 safeguarding issues raised are bi-directional. ADRTs are misunderstood and
9 assumptions are made that 'best interest' decisions can be applied by experts against
10 individuals' wishes. On the other hand, awareness of and possible reform to the
11 making of advance decisions may offer an enhanced means of safeguarding in
12 difficult times.
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16 COVID-19 has drawn our attention to domestic abuse under lockdown but has
17 perhaps occluded our focus on wider abusive structural factors that may have a
18 significant impact on risk and well-being. Most current social and health policy and
19 practice development in the UK draws upon normative assumptions; a hidden, taken-
20 for-granted-ness (Parker, forthcoming). However, policy developments often have
21 unintended and 'hidden' consequences (Merton, 1936). So years of retrenchment in
22 public spending and health service reform led to a lack of intensive care equipment,
23 personal protective equipment and failure to implement prior planning for pandemics
24 (Henley, 2020). There was a lack of appropriate government guidance in dealing with
25 an emergency and, as a result, the important consideration of triage when facing the
26 COVID-19 emergency. What began, perhaps, as a stretched service's approach to an
27 oncoming crisis brought to attention the socially constructed risks of being placed in
28 particular categories and a philosophical dilemma of where, how and to whom to
29 allocate scant resources. This represents a safeguarding issue at policy, practice and
30 personal levels.
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34 Unintended consequences have been recognised for a considerable time (Merton,
35 1936). Mitigating these is, however, problematic (Urry, 2016). Excavating the norms
36 on which thinking is based prior to the formulation of policy and the active
37 participation of citizens can offset some of these issues. It is our contention that a
38 campaign of raising awareness about and encouraging the use of ADRTs can assist in
39 protecting the rights of individuals and in creating a moral base for triage assessments
40 in future pandemic and emergency situations. They guard against potential
41 discriminatory abuse as well as the physical and psychological abuses sometimes
42 associated with poor treatment decisions and practices.
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45 **ADRTs and the refusal of medical treatment**

46 Individuals with capacity have the right to give or withhold consent to medical
47 treatment (Lynch, 2011). The Mental Capacity Act (MCA) 2005 sets out mechanisms
48 whereby people who lose capacity can also have their decisions respected. Alongside
49 ADRTs are Lasting Powers of Attorney for Personal Welfare (LPA) and Court
50 Appointed Deputies. The latter two are forms of substituted decision making whereby
51 someone else is given the legal authority to make decisions about the individual but
52 acting within one of the foundational principles of the MCA which is that anyone
53 making decisions on someone else's behalf must be acting in that person's best
54 interests (MCA 2005 s1 (5); see also Baroness Hale in *Aintree University Hospitals
55 NHS Foundation Trust (Respondent) v James (Appellant)* [2013] UKSC 67 paragraph
56 45).
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ADRTs were introduced into the MCA in an attempt ‘to codify and clarify the current common law rules’ (Department for Constitutional Affairs & Department of Health, 2005, para 84), although it was recognised that many people, including professionals, had ‘deep rooted personal, moral, religious and ethical views’ that needed to be addressed (Lord Chancellor’s Department, 1997, para 4.2). Despite the safeguards which the government attempted to introduce into ADRT, those views did not necessarily dissolve for all clinicians. A headline from the London Evening Standard (2007) published the day before the new law came into force stated, ‘We’ll fight backdoor euthanasia and risk jail say doctors’, reflecting some doctors’ and health care professionals’ perspectives who found the topic extremely emotive. This echoes an experience had by one of the authors (Lyne) who, during a training event in 2006, was told, very firmly, by a senior member of nursing staff that she had ‘come into nursing to save lives, not to let people die’. Current fears, however, reflect a reverse concern that decisions will be made to refuse treatment and allow death of certain groups based on discriminatory assumptions of treatment viability (Alzheimer’s Society, 2020). ADRTs would allow for ethical discussion and decision-making.

ADRTs are set out in sections 24-26 of the MCA. They can only be made by persons over 18 who have capacity at the time of making. ADRTs have to be both ‘valid’ and ‘applicable’. For instance, an ADRT would not be valid if the person has withdrawn it, has made a subsequent LPA conferring the relevant powers to the Attorney, or has acted in anyway which is inconsistent with the terms of the decision (MCA, 2005, s25 [2a, b, c]). An ADRT would not be applicable if:

- i. the person is capable of making the decision at the time it needs to be made,
- ii. it applies to treatments not specified in the decision,
- iii. conditions specified in the decision are absent
- iv. there are reasonable grounds to suspect that the current circumstances were not anticipated and if they had been this might have altered the person’s intent.

The applicability criterion is particularly relevant to the situation at the outset of the pandemic. In addition, whilst ADRTs can be made verbally, if the ADRT is in relation to life sustaining treatment then it must be written down, witnessed by a third party and contain a statement to the effect that ‘this advance decision stands even if my life is at risk’ MCA 2005 s25 [5] & [6]). In relation to the COVID-19 situation, it is likely that most ADRT would have to be written in this form in order to prove effective. SCIE (2020) argue that it is unlikely that people could write ADRTs in relation to COVID-19 testing as this is not treatment but any expressed wishes would need to be taken into consideration if making a best interest decision.

Section 24(1) MCA 2005 articulates the effects of an advance decision in empowering people to refuse specified treatments when they lose the capacity to give or refuse consent to it. Section 26 (1) states that making an advance decision that is valid and applicable has the same power as a decision made at the time by someone with capacity. Health care practitioners are bound to it regardless of whether it is considered unwise.

However, there are criticisms of ADRT (Morris *et al.*, 2017). On a practical level, it is clear that ADRTs will not work if the maker does not tell anyone of their existence.

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3 The Code of Practice (2008, para 9.38) sets out ways in which the existence of an
4 ADRT can be checked including recording the decision in healthcare records or
5 carrying a card. Recording the decision in healthcare notes, however, is not infallible
6 (Paduano, 2017).
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9 Poor understanding of ADRTs among health care practitioners is also seen to hamper
10 their effectiveness (House of Lords, 2014). However, it is with the onset of the
11 pandemic, concerns were raised that advance decisions, especially with DNACPR
12 notices attached were being adopted in a blanket fashion for certain groups deemed
13 'vulnerable' to the effects of COVID-19. This suggests a misunderstanding of ADRTs
14 underpinned by an 'expert' allocation of certain groups into categories for no
15 treatment that removes the voice and rights of the individual and becomes a serious
16 safeguarding issue to protect people from the actions of those trusted to care for them.
17 Michalowski (2005, p.959) points out that ignoring ADRTs or misunderstanding them
18 can result in 'an invasion of his or her bodily integrity'. Concern about this grew with
19 the Nursing and Midwifery Council (NMC) Chief Executive quoted as saying, 'In
20 recent weeks I have been disturbed by reports of blanket DNACPR orders being
21 applied to groups of people without their involvement or any individual assessment of
22 their needs. This is completely unacceptable' (Jones-Berry 2020). The NMC and
23 General Medical Council issued a joint statement prohibiting such actions. This was
24 followed by a further joint statement from the British Medical Association (BMA),
25 Care Provider Alliance (CPA), Care Quality Commission (CQC) and the Royal
26 College of General Practice (RCGP) who reiterated 'It is unacceptable for advance
27 care plans, with or without DNAR form completion to be applied to groups of people
28 of any description' (RCGP, 2020). Millington Sanders (2020) provided clear question
29 and answer advice in her blog for the Royal College of General Practitioners to offset
30 these misunderstandings and to enable individuals to make ADRTs in an informed
31 and non-pressured way. Ruck Keene's (2020) analysis of decision-making in a time
32 of COVID recognises the complexities and misinterpretations that may occur.
33 However, he argues that supported decisions may have a greater role in effecting
34 positive outcomes and respect for those individual decisions.
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40 Addressing misunderstandings and lack of knowledge of ADRTs will help offset
41 some problems and help to safeguard adults. However, the lack of standardised
42 practice acts as another potential risk. Because ADRTs for non-life sustaining
43 treatment can be made verbally and also perhaps because there is no recognised
44 national format for written ADRTs, there is no national record of either the numbers
45 or types of ADRT in existence beyond estimates. Kitzinger and Kitzinger (2016)
46 recommend 10 ways in which the uptake and use of ADRTs in Wales could be
47 promoted including the use of standardised quality-controlled forms and electronic
48 upload to the Welsh care record. There is no reason why these recommendations
49 shouldn't apply equally to England. One of the barriers to uptake identified in this
50 report is that some people are sceptical about an ADRT being effective in practice,
51 worrying that professionals may simply ignore what is written or be unaware of the
52 ADRT's existence.
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55 Access to them would seem to be a particular problem in a fast moving and ever-
56 changing clinical environment as recently seen during the pandemic. How does a
57 clinician balance the urgent lifesaving tasks with the need to see the patient as an
58 individual? This is, perhaps, where advance care planning could really have an
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3 impact, whilst at the moment it seems that ADRTs are used to make practitioner-led
4 decisions based on unconscious biases of usefulness of life and value of life rather
5 than appropriately seeking the voice of the person (Curtis *et al.*, 2020). It would also
6 add an important dimension of moral rather than clinical and evidence-based
7 decision-making that is so important for end-of-life-care (Coulthard, 2020).
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10 Emanuel *et al.* (2020) argue that the time constraints experienced in pandemic
11 treatment counts against taking quality of life and quality adjusted life years into
12 account. They argue that priority for treatment should be given to patients with a
13 reasonable life expectancy although they don't attempt to define what "reasonable"
14 means in this context. They also argue that "...encouraging all patients, especially
15 those facing the prospect of intensive care, to document in an advance care directive
16 what future quality of life they would regard as acceptable and when they would
17 refuse ventilators or other life-sustaining interventions can be appropriate." (p2052)
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20 Curtis *et al.* (2020) recognise the importance of addressing questions of ADRT and
21 DNRCPR notices following COVID-19 and candidly recognise that the pandemic has
22 led to an increase in discussion, at least, of DNR notices written by responsible
23 clinicians in the USA. The dangers in an over-stretched NHS hospital are rife. They
24 recommend moving towards a system of informed assent and having such
25 conversations with relatives and loved ones if it is no longer possible to speak with
26 the patient. This accords with the court's decision in *R (Tracey) v Cambridge*
27 *University Hospitals NHS Foundation Trust & Ors*. Such conversations also go some
28 way towards safeguarding the patient's rights under Article 8 European Convention
29 on Human Rights as outlined in *Winspear v City Hospitals Sunderland NHS*
30 *Foundation Trust*.
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33 Drawing an analogy from theology, we can identify two separate approaches in
34 assumptions made about ADRTs that have a bearing on adult safeguarding. A
35 kataphatic approach (what can be said) recognises the stated directive and decision of
36 individuals in certain circumstances through an express ADRT. An apophatic
37 approach (what cannot be said) demands we do not make assumptions about people's
38 wishes where there is no ADRT. If we are to develop advance decisions and clinical
39 practice in ways that safeguard individuals from unwanted treatments, or from the
40 withdrawal of treatments where this has not been clearly stated, we need to improve
41 the accessibility and visibility of individual decisions and to note the specificity of
42 ADRTs. A more explicit approach is necessary.
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46 **Ways forward for the future**

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48 The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
49 (Resuscitation Council UK, no date) is increasingly being adopted across healthcare
50 providers. It provides a basis for advanced informed consent, and a discussion of
51 informed assent later. ReSPECT emphasises that the heart of the process is a
52 conversation between the patient/ patient's family and the clinicians. This
53 conversation is then recorded so that everyone knows what decisions are acceptable
54 should the patient lose capacity. It is especially relevant for clinical decision-making
55 which, as we have seen in COVID-19, is often undertaken under considerable
56 pressure. Whilst not being an ADRT in its own right, ReSPECT can lead to an
57 advanced care plan which contains details of the patient's wishes, the clinical
58 recommendations for care and an agreed DNACPR decision where appropriate and is
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recommended by Millington Sanders (2020). This partnership type working is far more attuned to the ethos of the MCA, aspects of the European Convention on Human Rights, the Care Act 2014 and Social Services and Well-being (Wales) Act 2015.

The RCUK stress on their website that ReSPECT can be for anyone but will have increasing relevance for those who are seriously unwell. This highlights part of the problem with the current process of ADRT and advanced care planning: generally these decisions are often only made at a stage when the person is already unwell or has received a diagnosis. Perhaps there needs to be a societal change which embraces discussions regarding life including illness and death and steps taken earlier to outline one's own preferences. This would allow clinicians and health and social care practitioners to make informed and ethical decisions in respect of people in high-risk groups facing illnesses such as COVID-19 and will move away from the potential for widespread abuse to a person-centred approach to decision-making.

In any future work to promote societal change education will be important. Not only do we need a competent and confident work force in our hospitals who know the law and how to apply it, we also need a much greater understanding within the population as a whole. One can only give informed consent if one is truly 'informed'. But this is an area of life where there are many "unknown unknowns" as memorably suggested by Donald Rumsfeld. Indeed, the concept of informed consent is hotly contested (Parker and Ashencaen Crabtree, 2016). What is needed in respect of advance decisions and planning is the amplification of information, the debunking of myths and simplifying the process for completion. The authors have referred elsewhere to the work of Kitzinger and Kitzinger (2016). The first recommendation from their work is the promotion of public health education especially by providing key information in public spaces (they suggest a message on the side of a bus). They also suggest normalising ADRTs by making information freely available such as is done for other illnesses including leaflets and electronic information in doctors surgeries.

However, the need to have ADRTs freely available and accessible for relatives and clinicians also needs to be addressed. If a true partnership approach to health and social care is adopted this should mean the capacity to lodge advance decisions and plans alongside medical records or within an accessible legal repository. There is time post-death to identify, read and act upon a Will, there is little such time in respect of advance decisions, especially in a pandemic.

Conclusion

It is clear that we need to reform practice and guidance in respect of ADRTs and that we see this as a safeguarding issue. If ADRTs are not well understood or ignored then individuals are placed at risk of considerable distress through the receipt of unwanted treatments. Ignorance also potentially increases clinical deliberation and causes time delay when a thorough knowledge of and respect for advance decisions and clinical planning allows clinicians to work alongside individuals and families to achieve desired outcomes. Whilst psychological and physical harm may result from a failure to act on ADRTs, it is perhaps the potential for discriminatory abuse and acting on unquestioned assumptions that raises the clearest safeguarding issues. In order to avoid such abuse and assumptions we need to ensure clinicians are using advanced care planning well, have a good understanding of ADRT and are empowered to respect them when valid and applicable.

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3 As part of a drive to increase awareness and understanding a reflexive approach to
4 policy-making and clinical practice is necessary. Thus the assumption of clinician as
5 'expert' must be subject to critique when it comes to personal decision-making. The
6 use of potentially meaningless words such as "reasonable" quality of life as espoused
7 by Emanuel *et al.*, needs All clinicians and practitioners should be exposed to
8 unconscious bias training, recognising that marginalised groups are often
9 discriminated against unknowingly, structurally and through processes and
10 procedures. In practice this means that ADRTs should be accorded respect and people
11 with no ADRT receive equitable treatment to everyone else regardless of different
12 characteristics circumstances and conditions. Whilst an advance decision would,
13 therefore, safeguard, not having an ADRT should not place individuals at any greater
14 risk because of assumptions made about certain groups.
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18 As Mr Justice Hayden said in *Barnsley Hospitals NHS Foundation Trust v MSP*, "In a
19 real sense this is not a case about choosing to die, it is about an adult's capacity to
20 shape and control the end of his life. This is an important facet of personal autonomy
21 which requires to be guarded every bit as jealously for the incapacitous as for the
22 capacitous." (paragraph 47)
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25 This paper has argued that we need to move from a professional led health and social
26 care service to one where the individual is routinely viewed, at least as a partner, if
27 not the decision maker. Highlighting personal autonomy in this fashion should lead to
28 better decisions, less abuse and a restoration of trust between professional and patient.
29 Such an approach accords well with the Patient and Public Involvement policy
30 championed within the NHS (NICE, 2020). It respects the individual and rather than
31 detracting from clinical expertise and judgement it allows agreed decisions to be
32 reached on what is best for the individual in respect of treatments. Alongside this it
33 honours the spirit of ReSPECT for clinicians. Advance decisions and clinical
34 decision-making needs to move together to develop partnerships that safeguard the
35 person, and by the same token, the clinician.
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