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Living up to a good death: Complexities and constraints in end of life choices

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I. Introduction

The concept of choice has gained favour with politicians and policymakers over the past two decades as a means of driving down costs, driving improvements in healthcare, and empowering patients in decisions about their care. It is a concept equally taken up by patients and families and now appears to have secured its place as a moral imperative in the public imagination. In the UK NHS, as with other high income healthcare systems, choice has become a key principle guiding the way that healthcare is organised and delivered, a principle clearly seen in healthcare policies such as the recent white papers *Liberating the NHS: No decision about me, without me* (1) and *Building on the best: choice, responsiveness and equity in the NHS* (2).

Recently, attempts have been made to apply the logic of choice to the context of care at the end of life (3). The *End of life care strategy: Promoting high quality care for all adults at the end of life* (4), for example, emphasises the need to understand patients' preferences and facilitate their choices as they approach the end of life, with a particular focus on where they die. This was furthered in 2014 by a UK government endorsed independent commission for the purposes of advising on "how to expand choice to improve end of life care for adults" (5). The terms of reference for the review (6) illustrate how choice is seen by policy makers, where it exists not to provide options *per se*, but as a key means of achieving a "good death". Yet, what is meant by a good death is unclear and what has been heavily debated within academic literature is, within end of life care policy, "treated as a relatively unproblematic ideal and goal" ((7):p79). Here, a good death is set around key elements where the dying person dies free of pain and symptoms, in familiar surroundings and in the company of close family. Moreover, principles such as dignity, respect and autonomy are highly valued, principles themselves connected with discourses of choice.

These policy initiatives represent one small albeit visible locus in which the ideal of choice is sketched out and made productive. They sit within a much larger landscape wherein such enterprises as lobby groups, charities and policy think tanks as well as diverse academic communities drive forward to increase the possibilities for patients to decide on their own care and treatment. Within this broader landscape the idea of choice exists in diverse accounts complicating its application and having important implications for the type and quality of care people receive, how and where they receive it, and how they, and those close to them, feel satisfied with that care.

In this chapter, we explore two central accounts of choice: the *market version of choice* and the *civic version of choice*. We introduce the ideas that underpin each version and discuss the ways in which patients are implicated and defined in relation to them. We then discuss how each version becomes complicated in the context of end of life, taking the ideal of a "good death" (Figure 1) as our central point of reference. Our aim is to outline tensions in the choice agenda and to highlight the complexities inherent in the application of choice to care at the end of life.

FIGURE 1 HERE

II. Economics: market failure and choice

Market failure in healthcare

The conditions necessary for perfect competition to prevail are rarely present in the market for healthcare (8). In healthcare, markets are characterised by information asymmetry (including between patients and providers as well as that arising from the irreducible uncertainty that is the nature of many illnesses), lack of competition between providers, the presence of public goods and the existence of externalities (8). Even where markets do exist and function otherwise well they may still fail to deliver outcomes that satisfy societal objectives other than economic efficiency. Of particular concern with healthcare is where markets fail to achieve objectives relating to equitable access and provision of care across areas such as age, ethnicity, other socio-economic factors, and diagnosis. As a result, it is common for governments to act to achieve equity related goals through high levels of intervention in the market. This leads to a highly regulated market place and thus the power of markets to deliver efficient outcomes is curtailed. Achieving a balance between efficiency and equity goals drives much of health policy.

Achieving efficiency objectives subject to equity constraints (and *vice versa*) therefore requires further government involvement in healthcare. Bevan and Fasolo (9) provide an overview of the different governance arrangements that might be applied to public systems in order to meet societal aims. They class these as altruism, hierarchy and targets, reputation, and choice and competition (9). In the UK, some manner of each of these variations have been applied with the NHS since its inception.

In the English NHS all of these governance frameworks have at some time been implemented. The dominant governance approach from the inception of the NHS has been *Altruism*, an approach reliant on professional motivations and no external incentives. Bevan (10) argues that this approach led to a system where failures were tolerated and successes ignored. In recent decades focus has switched to methods emphasising external incentives, such as *Hierarchy and targets*, *provider Reputation* and, most recently, the *Choice and Competition* based quasi-market mechanism (for a more detailed overview of the history of NHS governance approaches see Bevan and Faloso (9)). This competition-based system generates incentives for both consumers and providers of healthcare. It involves more choice for patients over when and where to be cared for and payments to providers based on patient episodes of care. From the perspective of the patient, the quasi-market is believed to lead to benefits through the exercise of choice, giving them greater control over their healthcare and allowing them to determine what aspects of the experience matter most (11). For providers this quasi-market approach encourages them to improve care quality, thereby attracting more patients and more income. To this end, the provision of choice has thus itself become an objective of the English healthcare system – that patients have a choice has come to be seen as a benefit in and of itself (6;12).

End of life care is in this sense no different from any other healthcare market and the choice agenda has influenced end of life and palliative care. Patients and the public are routinely questioned as to their preferred places of care and death (13), GP practices are eligible for payment through the Quality Outcomes Framework if they record patients' preferred place of care on palliative care registers (14) and research frequently compares preferred versus actual place of death (13;15). This is a natural progression within a policy agenda that prioritises patient choice as a means of

improving outcomes. Yet some have questioned the role choice should play in end of life care. Can choice over care provision at the end of life be meaningful? Does the economist's assumption of the rational consumer with consistent, stable preferences hold in healthcare, especially at the end of life? What happens to those who lack capacity to express a choice and is choice as a lever of improvement sufficient to ensure that the care they receive will be of high quality irrespective of where it happens? How can choice account for differences in preferences between those providing care, those receiving care and the friends and family of the care recipient?

Homo economicus

At the core of textbook economic theory is the idea of the individual as a rational, utility maximising agent with preferences, known as expected utility theory. This rational being ranks and then chooses between the available set of goods to consume. As such, the starting point for the classically trained economist when thinking about how people make choices is to consider the rational individual seeking to maximise their utility (8). The rational individual is one that is assumed to know what they want and will, subject to constraints, act in such a way as to achieve that.

Underlying this idea of preferences are the assumptions of completeness and transitivity¹. Any set of preferences must be complete in such that when faced with a series of alternatives, the individual must have an opinion on which they prefer. Where there are two alternatives, *a* and *b*, the individual should be able to specify whether they prefer *a* or *b* or are indifferent between them. The second assumption about transitivity follows from this. The rational individual's preferences must be transitive, such that if the individual prefers *a* to *b*, and *b* to *c*, they must then prefer *a* to *c*. Given these two assumptions, it follows that the rational individual when making a choice will rank all of the available alternatives in a way that satisfies the transitive property and then choose that alternative that will maximise their utility, subject to constraints (such as budget).

So if it is assumed that the patient is a rational agent making utility maximising choices about health and health care, then it can be argued that the levers of choice and markets can be used to improve health and healthcare provision. Giving patients greater choice in which goods to consume will lead them to choose those consumption bundles that maximise their utility. Subjecting providers to patient choice will require them to deliver the goods of interest to the patient. This approach puts the patient as consumer at the centre of healthcare decision-making. This is the *Choice and Competition* approach as described by Bevan and Fasolo (2013). It is argued (most notably by Le Grand, 2003) that this approach can harness both altruistic and selfish motives of providers and should be the primary policy lever of governments to improve public services.

Yet accepting the primacy of the *Choice* model has significant implications. It requires that in the context of healthcare patients can be rational agents. Recent theoretical and empirical evidence challenges this assumption. This is the subject of Section III.

¹ Completeness requires that all possible options are ranked according to preferences between them. Transitivity is the principle that if an option *a* is preferred to *b*, and *b* is preferred to *c*, then *a* must be preferred to *c*.

III. Deconstructing homo economicus

It is increasingly the case that expected utility theory and the idea of the rational agent are being challenged, both in theory and by empirical evidence. Two of the most notable critiques come from outside the realm of economics. The first of these is from a philosophical perspective and is typified by Hausman (2012) and the challenges he presents to economists about the way they conceptualise preferences, self-interest and choice. The second is exemplified by Kahneman (for example, see *Thinking Fast and Slow*, 2012) and focuses on the psychology of decision-making. The earlier work of Kahneman and Tversky (1979) led to the development of Prospect Theory and provided early evidence of the way people actually make choices and how this conflicted with expected utility theory. Over time continued empirical evidence has been generated to illustrate how individuals do not always conform to the assumptions of rationality made about them by economists.

Hausman's (2012) critique of the rational agent focuses on the assumed link between preferences, choices and self-interest. In the classical model, as described above, the agent ranks all options and chooses the one that maximises utility subject to constraints. From this process it is argued we learn about people's preferences in one of two ways (Sen, as described by Hausman (2012)). The first is that options are ranked according to the expected benefit in terms of the individual's self-interest. The second is that preferences are revealed through choices. Hausman critiques both of these views and these critiques have important implications for thinking about patient choice at the end of life.

Hausman's first critique focuses on the link between preferences and self-interest, or what he calls 'expected advantage ranking'. Hausman, in discussing Sen's views, describes the standard view of preferences as expected advantage ranking as synonymous with the individual being better off (that is, having greater utility). In this view a person prefers x to y because they believe they will be better off from x . But as Hausman highlights, a person's preferences may be dependent on many factors that do not directly relate to their own wellbeing. If so, then this view of preferences does not hold. That this is the case in end of life decision-making is evident. For example, when discussing place of death, patients often consider the impact of their preferred place to die on their family as well on themselves (3). We discuss this further in the section citizenship. Clearly for some individuals preferences are influenced by factors other than their own wellbeing, suggesting merit in the Hausman critique of preferences as self-interest.

In his second critique, Hausman turns to the idea that choices can reveal preferences. In this view, utility maximisation and choice are synonymous and give rise to revealed preference theory. Hausman argues against the idea that choices can define preferences. At the core of this critique is that preferences can only be defined by choices when considered alongside beliefs. That is, it is not possible to say that a person who chooses x over y prefers x unless we understand their beliefs about x and y . In end of life care, a person may choose to die in hospital because of a fear of unmanaged pain, whereas their preference would be to die at home. If the patient is made aware of the options available to manage pain at home they may choose differently to better reflect their preferences. A public policy that assumes that choices reflect preferences – without accounting for beliefs – will potentially lead to suboptimal outcomes. Patients in the current model are placed in a position of having to make choices owing to a set of assumptions about rationality, utility and preferences that may not hold. In addition, they will often be making choices from a position of low information (given the acknowledged information asymmetry that characterises healthcare markets). That these choices are frequently interpreted as preferences in turn distorts the

information feedback loop to policy makers, who may see the making of a choice as a positive outcome in itself, given that choice is assumed to reflect preference.

While Hausman focuses on the conceptual links between preferences, choice and welfare, others, notably Kahneman and Tversky, have empirically tested assumptions about rationality and found them wanting (16). The work of Kahneman and Tversky that led to Prospect theory (16;17) characterises choice as a decision between expected losses and expected gains rather than final assets (or outcomes). In their early experiments they found that people consistently misestimate the expected gains and losses from decisions and treat decisions in ways that lead to inconsistent preferences, dependent on how the choice is presented (17;18). This work has been replicated by others (for example, see Abdellaoui et al (19) or Story et al (20)) and refined so that we now understand in much greater detail the role of heuristics and loss aversion in decision-making. Again, this can be seen in end of life care decision-making. Recording the preferred place of death has become an indicator of care quality (14), and many have argued for the opportunity for more patients to die in their preferred location, typically at home (21). However, it has been found that preferred place of death changes with age, a useful proxy for proximity to death (22;23). This may reflect changes in time preference for different outcomes or a greater aversion to losses associated with death occurring in a particular place. Story and colleagues (20) have recently found that people are unlikely to exhibit fully consistent decision making over time, though stable preferences is an assumption of expected utility theory.

Hausman's critiques of how economists frame preferences in the context of decision-making are highly relevant in healthcare and in end of life care. To successfully place the patient as consumer at the core of how health is directed and "done" requires dependence on assumptions about rationality and preferences that arguably do not hold. It is also evident from the empirical work of Kahneman and others that even where we assume rationality, people are poor predictors of the expected advantage of an outcome. Casting patients in the role of consumer in order to drive improvements in the system is dependent on the assumptions about rationality holding. Yet, given the evidence, how can we then assume that patients are capable of making rational decisions in their best interests? On the other hand, despite empirical evidence and arguments against patients as rational consumers, the autonomy of the individual in healthcare decision making is a key foundation of ethical treatment (24). From the perspective of the patient at end of life, it can be agreed that they have a right to be given autonomy over what happens to them and that includes the freedom to make mistakes when choice is viewed through the lens of the utility maximising rational framework. It is clear that patient choice has value beyond the policy context of service improvement. Choice can also be seen as a core part of what constitutes autonomy and how we engage with others in society. In the next section we discuss an alternative way of framing patients as choosers but not necessarily as economic agents.

IV. The civic version of choice

The civic version of choice works in different ways to that of the market and conjures different figures for patients. Rather than *consumers*, patients are conceptualised as *citizens* (25). This section introduces two accounts of citizenship that play on the categories of rights and duties in different ways. After introducing a model of citizenship in which patients are bound to health professionals

through particular contracts, we introduce a different way in which citizenship might work. Here, we discuss how the work of choice might be to produce the goal of healthy populations yet how this goal is complicated in the context of end of life.

The emancipated patient

While consumers are foremost defined in relation to markets, citizens are defined in relation to nation states (26); (25); (27). They are the units of the body politic given rights and duties through legal diktats. It is through these rights and duties that citizens are supposed to carry the nations of liberal democracies and hence govern themselves. As well as regulating affairs between the people and state, citizenship implies the governance of the affairs between people. This is done through the application of civic laws that frame the relations between people as contracts. These contracts embed a particular configuration of rights and duties to which different parties are bound to respect.

Many countries with highly developed health care systems have enshrined sets of “patient laws” that position patients and health professionals as citizens in relation to each other (25). When a patient seeks out or is referred to a doctor and is brought into contact with them in the context of the clinic, he or she implicitly enters a contract with them. The doctor, by agreeing to help the patient, does similarly. This obliges them each to act according to certain duties and bestows upon them certain rights (25). Central to the agreement, and underpinning the logic of choice according to the civic version, is the right of the patient to have jurisdiction over interventions into his or her body and life (28). Health professionals must allow patients to decide what happens to their bodies in the course of the diagnostic and treatment process. In order for patients to do this, health professionals must provide them with “the facts” about the various interventions and record patients’ decisions in the form of “consent”. As for patients, they must tell the truth and be open with everything that is relevant to their disease and, once a course of action is decided upon, they are expected to adhere to this.

While the market version of choice has been presented as a means towards public service reform, the civic version of choice might be described as a means towards ending medical “paternalism” (29); (28). Paternalism, characterised by the idea that the “doctor know best”, was said to produce patients as passive and unquestioning recipients of care who are subjugated to the will of the doctor. Since its portrayal by the sociologist Talcott Parsons in the mid-twentieth century (30), this asymmetry of power has been approached with much mistrust. It is in this context then, that civic laws and codes of conduct attempt to reconfigure the relations between patients and health professionals and imagine an emancipated position for the patient as citizen (25).

The responsible citizen

The civic version of choice is, however, not only about celebrating autonomy and self-determination. It is about responsibility (31); (32). And it is not only about taking responsibility for oneself, but also about taking responsibility for oneself in the context of society. In this way, the civic version of choice does not necessarily argue for individual choice as a simple principle (28). For a nation state to function properly, it must be healthy, and since citizens are, through the metaphor of the body politic, the units of nation states, the implication is that they must be healthy too. This idea resonates with observations that chronic illness is increasingly viewed as culpability in the face of known risks and how it is becoming less acceptable to enter and remain in a physically incapacitated state (32). The patient is reconfigured as taking responsibility for his or her condition and, given

information about risk and so on, they should choose to engage in healthy thoughts and behaviours (32). So in contrast to the paternalism and passivity described by Parsons (30), where the patient was said to occupy a state of “sanctioned deviance” and responsible only for accessing medical competence and cooperating with medical professionals, patients in the civic version of choice are made responsible in new and different ways.

These new types of responsibility are clearly embedded in policy programmes of health promotion that aim to construct and maintain healthy populations (32). Such programmes aim by and large to instantiate a condition of self-appraisal and reflexivity about health and illness within individuals that turns on the idea of health behaviours (31); (33). As part of this, programmes aim to condition choices towards activities deemed healthy and away from those deemed unhealthy. Built into these subtle shifts is a language of risk and individual susceptibility that is informed by the science of epidemiology (34); (32); (35). This works alongside a certain moral quality to health and illness as issues of responsibility and agency are distributed in particular ways along causal pathways (33). Choice is therefore reconstituted away from simply an individual concern to one that concerns populations, as individuals are to make “responsible choices”.

Health has therefore become a moral concern constituting the “affirmation of the life lived virtuously” ((36):p359). The healthy person is, in effect, symbolic of the ideal neoliberal citizen: autonomous, active and responsible, while those who deviate from this are made morally culpable (32). In this way, bodies and lives, instead of being the jurisdiction of patients and hence under their control, must be subjugated according to a set of moral parameters that is determined by the body politic (25). But what does it mean to be a responsible citizen at the end of life when the goal of health is no longer possible? And what responsible choices should citizens at the end of life make? At the heart of these questions is the issue of what it means to die well.

Citizenship at the end of life

Dying well has been a cultural preoccupation for centuries with the *Ars Moriendi* (“The Art of Dying”) among the earliest and most famous guides to dying and death in a Western literary tradition. Written in the early 15th century, the tract was intended to bring comfort and practical instruction to the dying man and his family according to the Christian precepts of the late middle ages. Among these precepts are exhortations that the dying make peace with their Maker, avoid temptations like despair, impatience and avarice, and approach death without fear. In the middle ages, these exhortations underpinned what it meant to die responsibly.

Yet the “ars moriendi” of the Middle Ages is very different to the “good death” of modern societies (37). While it was religion that undergirded earlier instruction, it is perhaps medicine that sets the frame in modern times; and whereas death was assumed to come quickly to people through infectious and unmanageable disease, we now live in a time when we are struggling to learn how to die from degenerative diseases and old age (37). It is in modern care practices that the question of how to die is bound up with practical questions and an ever-expanding list of choices about where we should die, what technologies should be available and used, what should be taken away, and for cultures where euthanasia is an option, exactly *when* to die. In the modern world, patients at the end of life are called upon to design their own deaths, whether viewed as consumers or citizens.

However, the practices and technologies we deploy in designing our deaths appear to evolve faster than the moral frameworks guiding their use (38); (39). This is reflected by a cultural ambiguity in

which social norms around dying and the application of technologies are so fragmented as to become meaningless and non-existent. We want deaths that are natural yet to know that we have tried everything. We want to be heroic and fight death yet graceful in our acceptance that the time has come. Such ambiguity is compounded by a rhetoric that we, as individuals, should author our own scripts for dying as we do for living (37). The responsible citizen at the end of life is therefore located betwixt and between multiple and conflicting narratives about what it means to die well; we die amid this cultural ambiguity.

In summary, patients according the civic version of choice are made autonomous, defined in relation to the state and bound to health professionals by sets of patient laws. However, their emancipation into citizens implies new responsibilities for health and an underlying logic for patients to make the right choices in accord with what is publicly configured as the moral standard. These standards have been constructed and recently used in programmes that attempt to fashion healthy populations. Citizenship, then, makes patients individuals in the image of the population and takes its shape in relation to the nature of the state (40); (27). It therefore represents both an impetus to act and a constraint upon acting (41), generating the paradox of the “patient chooser”: agents who are free to choose but systems that work upon them to guide their choices towards prescribed ends. However, what patients, as citizens, internalise about the choices they should make at the end of life is increasingly vacuous and contradictory. Whether this is liberating or frightening, an opportunity or itself a constraint, remains to be seen.

Living up to a good death

Choice is a complex phenomenon and the previous sections have introduced two versions of choice and a number of contexts that turn on and shape what choice means. Two main figures of the patient have been introduced: the patient as consumer who, rational and informed, makes choices according to preference, as ascribed by the conditions of the market; and the patient as citizen who has rights and duties that are ascribed through civic laws and social norms. It has also been introduced how these versions of choice position patients as instruments of change that allow either the reform of services or the maintenance of a healthy population.

The models of choice as presented here make the patient, whether consumer or citizen, responsible for their own health and thus responsible for the quality of their own death and by proxy for living up to the ideal of a good death. In the market framework, the patient who is ill or dies a poor death (however defined) because they failed to make choices has thus failed to exercise their rights as a consumer. In the patient as citizen view, the patient who falls ill is considered responsible if they have failed to conform to the norms or diktats urging them to live a healthy life or to die in a socially sanctioned fashion. A further complication here is the ambiguity that surrounds these norms, whether to die a “natural” death accepting that now is our time or to fight death through the application of an ever-expanding list of technologies. So dying is at once constrained by norms yet made ambiguous by the continual fragmentation of these norms. While this might appear to set a structure in which “anything goes”, in practice, some forms of dying are made acceptable and others unacceptable. This belies the social contexts in which choices are made, contexts that appear to be absent from choice policy where instead decisions are presented as the private concerns of the individual (3); (25).

Within the NHS, much policy is conceived within a framework of the patient as consumer (42). The thinking goes that if market conditions can be recreated in a non-market setting, then this will drive up standards (11) (and in some cases choice has been shown to improve outcomes (43)). But within this market patients are constrained by the choices that are made available to them by the institutions providing the service. For example, many treatments are only approved for access if they demonstrate cost-effectiveness. While this is an appropriate way to allocate scarce resources and achieve societal objectives in healthcare, it is inconsistent with the idea of the patient as consumer exercising choice. Choices are limited in other ways. Patients may choose a particular hospital or service, but they may not choose a specific clinician (42). If the quality of clinical practice varies within a service then choice here is in some sense meaningless – if the purpose of introducing choice was justified for clinical performance reasons, restricting choice of clinician prevents this.

Improvements in clinical performance are not the only justification for the introduction of choice in care. The dying patient may also be offered a choice of where to die for more patient centred reasons, such as the chance to have the death they want near to family or free from pain. Again here we see the contradictory influences of different models of choice at work. The burden of providing a good death is shifted from those providing care to those receiving it. If a patient fails to exercise choice over where or how to die, they have failed as consumers and citizens to exercise their autonomy. If they do make a choice but then don't receive the care they might need, they can be said to have chosen poorly.

In essence, whatever the model of choice implemented, the result is the restriction of that choice to a series of options presented as if a menu to the patient. The patient is free to choose, so long as they choose from the given menu. At the end of life, the patient as citizen might choose to die fighting or to die accepting death and in both cases surrounded by loved ones. But what seems unacceptable is to die scared, alone and in denial, for this would offend socially sanctioned responses to dying. Things are little different for the patient as consumer who must choose how and where to die well in advance of the event, irrespective of the fact that until the time comes they will be unaware of what the experience is like. If, during their last days and weeks a person decides they have chosen poorly they are unfortunate for, unlike goods in most other markets, there is no second chance to get it right in end of life care.

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