



Health policy, patient-centred care and clinical ethics

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Abstract

Rationale, aims and objectives Patient-centred care has been a central part of US and UK health policy for over a decade, but, despite its importance, the policy literature often fails to provide an adequate theoretical justification for why and how we should value it. This omission is problematic because it renders the status, content and appropriate evaluation of patient-centredness unclear. In this paper we aim to examine two different accounts of patient-centred care.

Method We draw upon methods of conceptual and ethical analysis.

Results We argue that neither of the two accounts of patient-centred care identified appropriately grounds patient-centredness because neither of them takes into account the inherently moral nature of terms such as 'respect' and 'dignity', terms that are central to discussions of patient-centred care.

Conclusions We suggest that clinical ethics can help to provide a theoretical justification for patient-centred care, and that clinical ethical practices can further patient-centred initiatives through ethics consultation, education and policy development and review.

Since the Institute of Medicine (IOM) published *Crossing the Quality Chasm: A New Health System for the 21st Century* in 2001 patient-centred care has become an integral part of US health policy in its effort to improve the quality of health care [1]. In the UK, Lord Darzi's 2008 report *High Quality Care For All* also placed patients at the centre of the Department of Health's drive to improve the quality of care provided by the National Health Service (NHS) [2]. But despite the high profile given to patient-centred care, the policy literature often fails to provide an adequate theoretical justification for why and how we should value it. While patient-centred care seems a self-evident good it requires, like all other models of health care, a strong theoretical foundation to inform its status, content and appropriate evaluation. Discussions of patient-centred care often fail to explicitly acknowledge the inherent moral dimension of this concept thus excluding a vital component of its justification and practical implementation. In the following sections we describe two accounts of patient-centred care and examine their justification.

Patient-centredness: a means to an end

In *Crossing the Quality Chasm*, the IOM suggest that health care constituencies adopt six aims to improve the quality of health care in the USA. These aims are safety, effectiveness, patient-

centredness, timeliness, efficiency and equity. The IOM defines patient-centeredness as care that is respectful of, and responsive to, individual patient preferences, needs and values, which is personalized care that gives patients the opportunity to exercise the degree of control they choose to have over their health care decisions [1]. In *High Quality Care for All* Lord Darzi states that for the NHS good-quality health care means care and treatment that is safe, effective and reflects positive patient experiences. Positive patient experiences are associated with personalized care, which is defined as care that is compassionate, dignified and respectful care. In other parts of the review Darzi relates improvements in quality to empowering patients, i.e. giving them more rights and control over their health care [2].¹

Improvements in patient-centred care are taken to require improvements in the information, choices and control patients have regarding their illness. For instance, in the Darzi report, the control that patients in the UK wield over where to receive secondary care is presented as an exemplar of patient-focused thinking. Darzi also emphasizes new initiatives to provide greater information to inform patient choices, initiatives such as expanding the NHS Choices web site to include information on the

¹ The principles underpinning the Darzi report are also reflected in the government's recent White Paper for the future of the NHS, *Equity and Excellence: Liberating the NHS*. Here, emphasis is placed on the value of patient experience and shared decision making [3].

quality of services offered across different care settings [2]. Similarly, the IOM emphasizes the need to improve the technological infrastructure to inform US patients about their available treatment options, to provide them with evidence about the outcomes of treatments and to enhance physician–patient communication and patient support services [1].

What justifies these policy proposals? Although the Darzi review and the IOM's *Crossing the Quality Chasm* both characterize patient-centred care as an independent aim of quality health care, the limited justifications offered in these documents suggest patient-centred care is, in fact, a means to other ends, namely safety, effectiveness and efficiency. In *High Quality Care for All*, for example, Lord Darzi emphasizes the way in which empowering patients to make choices about their own care makes it more likely that they will take responsibility for their own health, spending their own time and resources to address their health care problems, thus improving the efficiency of the system. He also discusses the health benefits of having better-informed patients. When patients are knowledgeable about the health risks of their life choices it provides them with the opportunity to make better choices, i.e. to eat healthier, to exercise, to stop smoking and so on. Often these kinds of choices make the care provided by the NHS more effective [2]. Similarly, in the IOM report, improving the technological infrastructure may inform patients about their illness and treatment choices, but doing so is construed as a means to making the health care system more effective in terms of improving outcomes, more efficient in terms of streamlining care and safer by reducing error [1].

Patient-centredness: consumer choice

In his article, 'What "Patient-Centered" Should Mean: Confessions of an Extremist' Donald Berwick discusses the dependent status of patient-centred care in the context of the IOM report [4]. In doing so he recounts some of the history of the IOM's program on the Quality of Health Care in America that led to the publication of *Crossing the Quality Chasm*. In particular, he draws attention to the incongruence between the aims that the IOM committee named and the problems that they identified in the system, namely, overuse, underuse and misuse. To the extent that overcoming the problems of overuse, underuse and misuse represent the IOM's priorities, then only two of the IOM aims are essential: safety (avoiding misuse), and effectiveness (avoiding under- and overuse) [4]. The other aims, including patient-centredness, are justified only to the extent that they further these other goals.

Berwick and others² believe that patient-centredness should be an independent aim of quality care. Berwick argues that the dependent status of patient-centred care suggests a model of quality assessment that still relies primarily on professional, rather than patient, judgments [4]. Moving towards a more consumer-oriented model of quality assessment would encourage recognition of the intrinsic value in patient evaluation.

In Berwick's view a more consumerist model of quality and thus patient-centred care is vindicated primarily because of the threat that the professional model holds for individual dignity. As he puts the point,

What chills my bones is indignity. It is the loss of influence on what happens to me. It is the image of myself in a hospital

² See for instance [5].

gown, homogenized, anonymous, powerless, no longer myself. It is the sound of a young nurse calling me, 'Donald,' which is a name I never use. . . It is the voice of the doctor saying, 'We think. . .,' instead of, 'I think. . .,' and thereby placing that small verbal wedge between himself as a person and myself as a person. It is the Clerk who tells my wife to leave my room, or me to leave hers, without asking if we want to be apart [4].

For Berwick this threat to indignity indicates a version of patient-centred care in which medical decisions are ultimately left up to the patient and/or their family. Moreover, he suggests that these decisions ought to be honoured even when they are at odds with professional judgment and evidence-based medicine [4]. He thus defines patient-centred care as the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances and relationships in health care [4].

But again we must ask, what justifies this account of patient-centred care and the policies that would develop as a result? Does dignity demand such limitations on professional input? Does respect and personalization require a model of health care quality assessment analogous to models of consumer choice?

II

The moral justification of patient-centred care

When policy makers evoke the language of patient-centred care; referring to 'respect' and 'dignity', and the importance of individual 'values' and 'needs', they invoke and deploy the language and concepts of morality. Yet that the values underpinning these policies are fundamentally moral values is typically unacknowledged [6]. Berwick appeals to the dignity of patients in order to justify the independence of patient-centred care as a policy objective and he associates respect for individual dignity with a consumerist model of health care. But he gives no consideration to whether this association is justified, or what is required of dignity for it to justify the independence of patient-centred care. Likewise, *Crossing the Quality Chasm* and *High Quality Care for All* fail to consider seriously what respect for, and the dignity of, patients entail, and how this might affect the status and content of patient-centred care. Construed as a means to safety, effectiveness and efficiency, the nature and function of patient-centred care is already compromised.

If we are serious about patient-centred care because it involves providing respectful, dignified and responsive care that is sensitive to patients' values, then we also should be serious about how to fulfil these objectives. Substantiating the moral concepts underpinning the rhetoric relating to patient-centred care can help to justify its status and content, and in turn help us to better evaluate it. Substantiating these concepts requires us to consider the nature of the obligations that we owe to each other, and, thus, an engagement with moral theory.

Respect and dignity

The application of the concepts of 'respect' and 'dignity' is controversial within medical ethics and we have no intention of

settling that controversy here [7,8]. Nonetheless, the philosophical writing of Immanuel Kant has been perhaps the most influential in defining the terms of this debate [9] and we draw upon Kantian philosophy to illustrate how one might go about justifying a policy that claims to respect the dignity of patients. For Kant, our duty to respect persons is derived from his second formulation of the moral law, 'Act so that you use humanity, in your own person as well as in that of another, always also as an end and never only as a means' [10]. Medical ethicists will be familiar with the mantra that morally good behaviour is that which respects humanity, i.e. our rational nature, as an end in itself.

Humanity should be respected as such because of our capacity to determine ends and choose means to achieve them; to decide, for instance, to become a doctor, to care for a loved one, or to buy a car, and then to form a plan to achieve these things. For Kant, respecting this capacity amounts to acting in ways that one can justify to others; setting ends and choosing means that conform to principles that anyone can accept. When I decide to care for my ailing mother, I act on the principle that we ought to help others in need. I respect others and myself insofar as this principle is one that anyone can accept. In other words, one respects humanity as an end-in-itself by acting from universalizable principles [10].

Kant claims it is because we have this capacity to set ends and choose means that we are also the source of value in the world [11]. For instance, when I decide to become a doctor, then I have reasons to study medicine. But it is the value of the end that we set – becoming a physician – that provides us with reasons to act and it is our will that confers this value in virtue of its capacity to set ends [11]. According to Kant our rational nature is the source of all value because humans alone are capable of setting ends. As such, our rational nature is itself unconditionally valuable, i.e. its value is not contingent on or comparable with anything else [11]. It is this unconditional value of our rational nature that Kant refers to as our dignity.

If we accept this understanding of the nature of respect and dignity, the question for policy makers becomes: how do we express the proper respect for the unparalleled worth of human rationality? This question relates to two different aspects of health policy. The first concerns the content of policies of patient-centred care, and the second concerns the status of patient-centred care as an aim of quality health care. We will consider each in turn.

Beginning with the question of content, how should we properly respect patients as persons? Unfortunately, there is no algorithm with which to answer this question and, indeed, many answers are controversial. They are controversial because it is often unclear, for instance, whether palliative sedation fails to respect persons as ends in themselves or under just what circumstances it is permissible to treat patients paternalistically in order to preserve their rational capacity [11]. The problem is that we must apply these moral concepts in concrete cases, i.e. we must use our practical reasoning, and in doing so there may be legitimate questions about whether some action does or does not respect dignity.

But simply asking informed patients and/or families what they prefer, or having them choose from a list of predetermined choices cannot clarify these difficult cases. Although *Crossing the Quality Chasm* and *High Quality Care for All* as well as Berwick's proposal often link such policies to respect and dignity, Kant shows us that the two are not consistent. For Kant treating persons with respect and dignity is not a matter of acting on informed individual

decisions, but rather a matter of acting on principles that express the worth of humanity. Sometimes doing so will be explicitly at odds with what informed individuals prefer.

Kant is clear that we can be mistaken in our reasoning, informed or otherwise. Respect for someone who is mistaken involves, on the one hand, listening to see if their judgments contain any truth, and on the other, working out where their reasoning went wrong so that we might illuminate their error [10]. Once again there is no algorithm for determining when a person's judgment contains truth or error, but at least for Kant respecting one's dignity requires those involved to use their reasoning skills to resolve such cases.³ Sometimes respect and dignity require clinicians to challenge patients, and sometimes patients must challenge clinicians. Thus, the Kantian model of respect and dignity provides clinicians with a significant role in decision making and undermines the consumerist model's straightforward acceptance of patient choices.

This digression into Kant is not meant to suggest that Kantian moral theory is the only appropriate one for justifying proposals of patient-centred care. Rather, it is meant to illustrate how engaging with moral theory is required to ground and substantiate patient-centred policy proposals. Nonetheless, even non-Kantians generally take respect for persons to require more than additional information and control. Students of John Stuart Mill, for example, while clearly linking respect to individual choices, make clear that the only choices that garner respect are those that somehow express the integrity of the individual making them. Choices and actions must be the result of desires that have withstood sufficient critical reflection [12].

Respect for persons also concerns a second aspect of health policy: the status of patient-centred care. Should patient-centred care be considered an independent aim of good-quality care as Berwick suggests, or as a means to achieving safety, effectiveness and efficiency as it is construed in the Darzi and the IOM reports? As we argue above, respectful and dignified care cannot be achieved by simply providing patients with more information, choices and control. Instead such care requires us to act, for instance, in accordance with principles that express the worth of our rational nature, or in accordance with choices that have withstood sufficient scrutiny. Thus, it is not clear that treating patients with respect and dignity will always further health care safety, effectiveness or efficiency. Sometimes it may be more efficient to follow disrespectful or undignified courses of action and, depending on how one defines effectiveness, respecting patients may not have any effect on treatment outcomes or it may have a deleterious one.

Yet our increasing regard for the role that individual values and goals play in the assessment of medical outcomes [13,14] makes it difficult to ignore patient perspectives simply because they do not improve the safety, effectiveness or efficiency of health care. Berwick's claim that the dependent status of patient-centred care gives too much weight to professional judgment suggests a kind of paternalism. It suggests that clinicians need not justify their actions to us. For Kant such behaviour is disrespectful and undignified. If our goal is to provide dignified and respectful health

³ The fact that clinicians have imperfect judgment does not speak against what respect and dignity require in these cases. Indeed as we will argue in the next section their imperfect judgment instead speaks at least in part to the need for hospital-based clinical ethics.

care than patient-centredness should be an independent aim of quality care.

Personalized care

In addition to respect and dignity, policies advancing patient-centred care place great emphasis on care that is personalized and responsive to individuals' needs, values and experiences. The idea behind this goal seems to be that by personalizing care to individual patients we avoid the imposition of unshared values that might contaminate decisions made by others on behalf of the patient. Personalized care thus protects against paternalism. But conceptions of personalized care that emphasize better information and consumer choice often ignore the values that shape the presentation of information or the choices offered.

Consider, for instance, the case of pregnancy reductions, i.e. reducing the number of fetuses in a single pregnancy. The moral permissibility of a pregnancy reduction typically rests on an unfavourable prenatal diagnosis in which 'unfavourable' is conceptualized as a significant risk of harm to the pregnant woman or the foetus(es). For instance, pregnancies with three or more fetuses are generally associated with gestational diabetes and low birth rates [15,16]. The Royal College of Obstetricians and Gynaecologists' (RCGP) multiple pregnancy study group statement refers to the increased incidence of foetal abnormality in multiple pregnancy and recommends that: 'Parents of high order multiple pregnancies (≥ 3) should be counselled and offered multifetal pregnancy reduction (MFPR) to twins in specialist centres' [17].

In these cases, 'harm' and 'health' are almost exclusively determined by clinical indicators. Indeed, it is the lack of clinical indicators of harm to the foetus or mother that morally differentiates elective reductions (reductions from a twin to a singleton pregnancy) from selective and high-end multi-fetal reductions [18]. While many have argued that elective reductions are morally impermissible or at least morally suspect, most take high-end multi-foetal reductions to be morally acceptable [19–21].

The main problem with these clinically driven definitions of 'harm' and 'health' is that they presuppose certain social values that can shape the context in which individuals are offered certain choices. Thus a woman with a multiple pregnancy of four fetuses would, on the basis of likely harm to the mother or the fetuses, be offered counselling about the possibility of a reduction, but a woman who wishes to reduce her twin pregnancy to a single foetus because she does not feel she can adequately support two children would not be offered counselling for the same reasons, i.e. as a result of the harm to the foetus.⁴ However, by not offering reduction to the mother of a twin pregnancy we fail to consider her values or her views on the harm that she faces. Harm is a function not simply of clinical outcomes, but is also a matter of extra clinical factors, for instance, what constitutes perfection and disability, the role of fertility in a good life, and questions regarding the amount of money needed to provide adequately for another person [18].⁵

⁴ Although she might be offered counselling on the basis of new research that suggests that twin pregnancies are significantly risky in terms of clinical outcomes. See, for instance [22].

⁵ In the UK for cases of abortion the concept of harm is considered more broadly, at least before 24 weeks gestation, illustrating an inconsistency in values between the two situations.

The moral permissibility of certain choices, such as foetal reductions, cannot be justifiably reduced to measures of clinical outcomes. Moreover, the role of values cannot be confined to the black box of individual patient decisions, as in many cases values will also determine the permissibility of providing patients with a choice in the first place. If we are serious about providing personalized and responsive care, we should be serious about engaging with the values that shape what counts as health; what counts as harm; what counts as illness and so on. This engagement requires not simply asking patients what they want, but rather considering the unspecified and undefended values that underpin our health-care policies and practices.

Clinical ethics and patient-centred care

Serious concern for dignified, respectful and responsive care requires an engagement with moral theory in order to justify and substantiate policy proposals for patient-centred care. Nonetheless, current US and UK health policies often fail to do so, and as a result the status and content of patient-centred care is unclear as is the best way to evaluate it. This lack of theoretical concern in health policy is not unusual. Take, for instance, the use of Patient-Reported Outcome Measures (PROMs). In the Darzi report, PROMs are highlighted as innovative measures that provide patients with the opportunity to express the effectiveness of an intervention from their own perspective [2]. But as Greenhalgh *et al.* and others have argued, PROMs lack a theoretical approach within which one might understand how they are meant to function [23–25]. This omission makes it difficult to evaluate the success of PROMs in augmenting clinical decision making and it makes it difficult to provide explanations when PROMs do not function as expected, or suggestions for how to improve them [23]. A theoretical framework for PROMs is clearly needed if they are going to continue to play a significant role in health policy.⁶

As with PROMs, policies of patient-centred care require a theoretical approach, but unlike PROMs there is already an area of health care that engages with moral theory in order to apply concepts such as dignity and respect to individual cases, and to the arena of institutional policies. This area of health care known as clinical ethics aims to improve the moral and ethical standards of patient care. Clinical ethics is, however, rarely associated with mainstream policy proposals for patient-centred care because, as we have shown, these policies tend to focus instead on improving the technological infrastructure and increasing the choices that patients are routinely offered. But clinical ethics and clinical ethics support services have much to offer patient-centred care initiatives.

III

Clinical ethics

Although questions regarding the ethics of medicine have been of interest to philosophers and physicians since the time of Hippocrates the emergence of medical ethics as an academic discipline only occurred in the 20th century. The development of clinical ethics, as we define it below, did not begin to appear in the USA until the 1970's and over a decade later in the UK [26,27]. Clinical

⁶ For examples of possible theoretical frameworks see [23,25].

ethics is a type of medical ethics, but one that concerns itself with clinical practice and often focuses on the moral and ethical issues that arise out of the clinician–patient/family relationship [28,29]. Similar to other areas of health care, ‘clinical ethics’ describes a field of research, i.e. a body of knowledge and skills, educational curricula for clinicians, and an aspect of patient care that is delivered ‘on the ground’ [30].

As a practice, clinical ethics manifests as a support service that draws on the relevant knowledge and skills to provide ethics consultations, education of clinicians, and the review and development of institutional policies that bear on topics with an ethical dimension. As a research endeavour, clinical ethics is concerned with topics such as the nature of ethical reasoning, how to make ethically justifiable decisions in the context of clinical practice and health care policy, and the evaluation of the support services that those working in clinical ethics provide to individual health care institutions. Clinical ethics could, and we argue should, have a key role in developing the required theoretical justification for patient-centred care.

Justifying and substantiating patient-centred care

Including clinical ethics in policy considerations can help to justify and substantiate patient-centred initiatives in part by providing a theoretical framework. Such a framework justifies patient-centred care by providing reasons for its provision; for instance, respect and dignity are required in order to convey the worth of human rationality. Clinical ethics helps to substantiate these initiatives by showing us, in a general way, what is required of respect, dignity and responsiveness if these concepts are to convey our human worth.

Clinical ethics can also substantiate patient-centred initiatives in a very practical and concrete manner: through the support that clinical ethicists provide in individual health care institutions. For example, a clinical ethics service in a hospital can contribute to the development of patient-centred policies by ensuring that such policies are grounded in an ethically justifiable framework that includes respect and dignity. They might review policies on end-of-life decisions or resuscitation to determine whether they are sufficiently responsive to patient preferences, or they might develop a policy on the permissibility of filming surgeries in order to ensure the dignity of patients under sedation. Through the provision of a range of educational and support initiatives clinical ethics services can facilitate the implementation of such policies.

The practice of clinical ethics also supports patient-centred care at the level of the individual patient–clinician interface. As we discussed earlier there is no algorithm for determining in concrete cases how to respect patients and treat them with sufficient dignity. Each case requires the application of practical reasoning, and, in medicine where new technologies often lead us into uncharted territory, it is not surprising that we are sometimes left with genuine questions about how to proceed. In these cases, clinical ethicists can be called upon to aid in the practical reasoning of a difficult case. Case consultations come to clinical ethics services in all shapes and sizes. For example, clinical ethicists may be asked to provide advice regarding the sedation of a particular patient who lacks capacity, or they may be consulted regarding whether a

confidence should be upheld or broken. They must then facilitate the appropriate use of moral concepts such as respect, dignity and responsiveness to the particular context of the individual cases thus aiding the decision makers in the provision of morally grounded patient-centred care.

These pursuits have the capacity to substantiate patient-centred care policies at the grass roots by taking a case-by-case, policy-by-policy approach in the hope that by doing so the contextual features of each situation can be given adequate consideration. This process in fact embodies the responsiveness that patient-centred care initiatives often strive to accomplish. Although clinical ethics activities concern topics that go beyond patient-centred care, questions of respect, dignity and responsiveness go to the heart of many clinical ethics pursuits. There is even evidence that those working in the field of clinical ethics understand their work as improving patient-centred care [31,32].

Proliferation and evaluation of clinical ethics

For clinical ethics to offer theoretical and practical assistance of this form in the delivery of patient-centred care it is important to understand the current nature and status of clinical ethics services within health care institutions. The provision of clinical ethics support is widespread and increasing. In 2007, Fox, Myers and Pearlman reported that 95% of US hospitals had or were developing ethics consultation services compared with the 1% that reported having a clinical ethics committee in 1983; and in the UK 82 NHS Trusts now have an active clinical ethics committee, compared with 20 in 2001 [33–36]. In the USA it is estimated that in the course of 1 year, 29 000 individuals spend more than 314 000 hours working on over 36 000 ethics consultations [33]. Endorsed by organizations such as The Joint Commission and The Royal College of Physicians, clinical ethics services have become more than a passing fad [37,38].

Nonetheless, these services are not without their critics [39–41]. One such criticism is that very little is known about the quality or efficacy of the support that is provided by clinical ethics services because there have been few attempts to evaluate these services [42,43]. As with any specialty in clinical medicine the mere fact that the specialty *can* contribute in a meaningful way to good patient care does not obviate, and in fact necessitates, the need for appropriate evaluation of the practice against agreed, evidence-based outcomes. Critics and even supporters of clinical ethics are often hesitant to link practical ethics support to public policy initiatives without evidential support for the quality of work they currently undertake [44]. But the lack of evaluative information regarding the support that clinical ethics services provide should not blind us to the fact that these services exist. This lack of information does not prevent clinicians and health care institutions from establishing and using these services, and it should not prevent advocates of patient-centred care from harnessing the work that they are already performing.

We are not suggesting that the research base of clinical ethics should not be improved. What we are suggesting is that those interested in patient-centred care should also be interested in the evaluation of clinical ethics services, precisely because improving the quality of patient-centred care depends on better understanding the efficacy of clinical ethics support. Clinical ethics has been largely ignored by advocates of patient-centred care, and yet it is the

only area of health care designed specifically to apply the very values that underpin the patient-centred movement. Without investment in clinical ethics, including its evaluation, advocates of patient-centred care will fail to justify why we should develop patient-centred initiatives either in theory or practice. This is because any serious consideration of patient-centred care requires serious engagement with moral theory, normative ethical reasoning, and the careful translation of ethical arguments into the delivery of health care to individuals in circumstances of moral uncertainty: the very activities in which a robust and effective program of clinical ethics research and practice is designed to engage.

IV

Conclusion

Policies of patient-centred care lack theoretical justification. This lack renders the status, content and appropriate evaluation of these policies unclear. As we have argued the justification of patient-centred policies requires an engagement with moral theory. Clinical ethics can help to provide a morally substantive justification and further patient-centred initiatives. In its research capacity, clinical ethics justifies patient-centred care by providing reasons for its provision and illustrating in a general way what is required in order to provide respectful, dignified and responsive care. In its capacity as a support service, clinical ethics helps to provide morally grounded patient-centred care.

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