

On challenges to respect for autonomous decision making in primary care

Clinical Ethics

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Abstract

Primary health care is characterised by timely and appropriate health care access, delivered continuously over time to a specific population, providing a comprehensive service, with coordination of care for those that need it. Practitioners deal with a multiplicity of clinical issues within longitudinal relationships, embedded in the context of families and communities. We propose that these aspects of primary care have a bearing on how matters of decision making are considered and implemented. Further, the standard account of autonomous decision making is not wholly adequate when applied to clinician–patient encounters in primary care. We add considerations of the impact of illness (however defined) and self-identity as also relevant to a more measured and full account. The context of primary care is quite different from that of secondary care. Although there are generalists who work in hospitals, we argue that this aspect and the other attributes of primary care generate special ethical considerations. One of these is how autonomy, or more fully, how respect for the principle of autonomy is considered and operationalised in community practice. In this study, we describe some theoretical aspects of autonomy and seek to apply, and challenge, these aspects in the context of clinical work in primary care. In doing so we will review the descriptors of primary care: why in essence it is different from other contexts of clinical work.

Keywords

Autonomy, primary care, patient relationships, clinical ethics

Introduction

The context of primary care is different from that of secondary care. Although there are generalists who work in hospitals, we argue that there are attributes of primary care that generate special ethical considerations. One of these is how autonomy, or more fully, how respect for the principle of autonomy is considered and operationalised in community practice. In this article, we describe some theoretical aspects of autonomy and seek to apply, and challenge, these aspects in the context of clinical work in primary care. In doing so we will review the descriptors of primary care: why in essence it is different from other contexts of clinical work.

Primary health care in the United Kingdom (UK) is characterised by timely and appropriate health care access, delivered continuously over time to a specific population, providing a comprehensive service, with coordination of care for those that need it. Practitioners deal with a multiplicity of clinical issues within longitudinal relationships, embedded in the context of families and communities. We propose that these aspects of primary care have a bearing on how matters of decision making are considered and implemented. Further, we argue that the standard account of autonomous decision making is not wholly adequate when applied to clinician–patient encounters in primary care. As generalists, we draw

on a diverse range of sources to support our arguments and offer a typical case by which to illustrate the themes in question. A clinical decision could be thought of as the end point of all the theoretical and practical approaches to respect for the principle of autonomy; therefore, we start with the theoretical underpinnings of autonomy in clinical arenas – an area not short of philosophical input in recent years.

Traditional views of autonomy

The most well-known ethical framework in clinical practice is advanced by Beauchamp and Childress.¹ The principle of respect for autonomy has joined their other three principles of medical ethics to be considered routinely in clinical decision making, where it is relevant to –confidentiality,

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disclosure, competence and shared decision making. Such a view of autonomy has been termed individualistic, encompassing notions of self-sufficiency, independence and self-interest.^{2,3}

By contrast, other authors such as Bergasma and Thomasma⁴ develop the importance of relationships in analysing the principle of respect for autonomy: both between clinician and patient, as well as between patients and their families. Further, Pellegrino and Thomasma⁵ state '*yet health care is a healing relationship conducted by two autonomous persons in the presence of human suffering*'. This is to suggest not only that both parties to a consultation have defining agency; but also, that the clinician's response to a patient's suffering affects the interaction; and consequently, the patient's decision making. Therefore, a fundamental question to consider is whether the agency of the patient is changed by the opinion, influence or even discussion of clinicians or relatives for any given decision. In one way, it could be said that a patient decision is fully autonomous if final and taken after the influence of others has been evaluated, considered and reflected upon. However, a strict view of the autonomy principle of Beauchamp and Childress might disallow this, as some form of moderation of the decision has been brought about by the action of others, so that it may no longer be considered individualistic. We describe this view as traditional in the context of clinical decision making. There have been challenges made to this traditional account of respect for autonomy⁶ including Donchin who argues that

a reformulation of autonomy is a positive conception of human agency that recognizes relational experiences as an integral dimension of individuality.⁷

In doing so she suggests that the principle of autonomy as fleshed out by Beauchamp and Childress is over-individualistic, citing similar criticisms from other authors such as Englehardt.⁸ In our view, a more relational consideration of an autonomous decision is relevant when analysing the way persons take (particularly difficult) decisions in their own health care. We begin therefore to describe a more developed view of what it might mean to respect autonomy in primary care.^{9–11} Such decision making, we may assume, is conducted with the well-being of patients as a direct goal. This implies that respect for the principle of autonomy has a clear value in outcome.¹²

A separate issue to consider is the relative position of respect for the principle of autonomy in the full Beauchamp and Childress framework of principles: whether there may be a lexical order to the four principles of autonomy, beneficence, non-maleficence and justice. This issue has been approached empirically by authors such as Page whose work suggests a priority to non-maleficence in the subject group considered.¹³ However, from a theoretical perspective, the resolution of dilemmas

where the principles may be held to be in conflict is more contested. Gillon,¹⁴ Shea¹⁵ and others have reflected on this problem and concluded that the issue of formal consent that flows from consideration of the principle of autonomy is of fundamental importance to the practice of medicine in all contexts. Therefore, at least conditionally we will regard autonomy as being of the highest priority.

Clinical respect for a patient's autonomous decision making seems a *sine qua non* in modern practice, and it is surprising to remember that this position is relatively recent.^{16,17} For clarification, by respect for the principle of autonomy we mean that a person should formally have control over their diagnostic and therapeutic decisions, excluding paternalist or other influences. Clearly, this is not an illimitable principle but serves as a broad statement from which to start. An autonomous patient decision in health care is predicated on four elements: the provision of adequate information about the projected intervention, a demonstration of its understanding, freedom to arrive at a personal conclusion, and the possibility of change of decision.¹⁸

In the next section, we seek to apply these kinds of discussion to the relatively unexplored area of primary care (medical ethics concentrating, as it often does, on the higher technological world of the hospital), where relationships of all sorts are part of the daily experience, and indeed often part of the healing experience of patients. To do that requires some description of the key features of primary care as well.

The clinician–patient interaction in primary care

Much scholarship has covered the nature of the clinician–patient interaction that takes place in primary care – this is usually concerned with its content, process and outcome.¹⁹ It is axiomatic that care cannot take place without the two main moral agents involved. The motivation for care is again usually but not exclusively the perceived suffering of the patient, who seeks out a health care professional to relieve it in an instrumental way. In primary care, one of those instruments is the relationship between clinician and patient, which is often longitudinal over months or years.^{20–23} This relational element, which is predicated on continuity is a key descriptor of primary care, and usually does not reflect most specialist practice. It is true that recent developments have led to care being increasingly team-based, with the potential for an erosion in such long-term relationships due to changes in the organisation and delivery of care. However, as Ahluwalia *et al.*²⁴ assert, continuity can be represented not only at an interpersonal level, but also via the primary care organisation itself and the information it holds on individual patients and their families. Primary care continuity has real health benefits, something which has recently been empirically demonstrated.^{25,26}

Given that relationships between doctors and patients are not merely, as May and Mead²⁷ indicate, ‘*a technical device for the delivery of care*’ but are founded on trust and personal obligation, we could also propose that lengthening relationships might serve to deepen these foundations. O’Neill²⁸ has described the doctor–patient relationship as a ‘*paradigm of a relationship of trust*’, and if this is so the closeness and length of archetypal relationships in primary care can only contribute to that depth. When considering relational care, the tradition of whole families being registered with the same practice or primary care organisation is significant. In fact, one of the many terms used to describe physicians who work in primary care is ‘family’ doctor (interestingly this prefix is not usually extended to other members of the team, perhaps because of the historical context).

In the UK, patients are registered with a primary care practice usually on a family basis: this formality is semi contractual (where the contract to deliver care on behalf of the Secretary of State for Health and Social Care is represented) and removes the clinician–patient relationship from the open commercial market operated in other systems. In other words, the care of the patient is not related to the transaction of money between both parties. And from this registration flows a continuing relationship between the primary care team and the individual and cared-for-family. Because of this continuing relationship, the ‘culture’ of the practice, on which we expand in the case study below, influences not only individual clinicians but also patients and their families.²⁹

Primary care is firmly situated in its community and practitioners thus need to be aware of, among other things, the degree of social disadvantage, the ethnic mix and the availability of local resources. In addition, it is for the most part the place where first access is available to patients, a front door to the wider health care system. This aspect cannot be underestimated in importance. When patients are ill, or in distress, or pain, or believe themselves to be so, the point of first contact between them and the health system marks the activation of a duty of care; in this instance, the restatement of a fiduciary relationship which it is to be hoped, will lead to a restoration of health or support in continuing ill health.

In each of such episodes, decision making will need to come about between a doctor and her patient. Clearly, this is not specific to primary care, as specialist care has its own qualifiers in consideration of decision making and consent, but which we see as qualitatively different. Viewing primary care as a sequence of individual consultations over an extended period has its own consequences. Information about the patient and his family is gathered over time, sometimes long periods of time, and clinicians thus can come to quite profound understandings about the narratives of patient experiences. It has been said that such care is often about the making of meaning in those experiences rather than a more technical resolution, a process more easily made in the context of a long-term relationship.^{30,31}

Finally, the notion of generalism deserves explanation here, freighted as it is with a variety of meanings in differing contexts. We use the term with the specific meaning described by Reeve as ‘expert medical generalists’ who take a biographical as well as a biotechnical view of their patients’ experiences, and who cover all presentations that patients (of any age) may offer.³² It is this combination of the biographical with the biotechnical over time which allows the relationship between clinician and patient to be used in the instrumental manner we describe above.

Thus far we have discussed what it is to conduct generalist practice, in a manner recognisable in many, but not all, countries around the world. It is of note that primary care is the main medical intervention by which population health care is improved, so that the sum of all individual patient interactions does indeed bring about a collective advance in health status. This could be described as a perspective from utility theory.³³ In the next section we use a case study to explore the influence of these key descriptors of primary health care on autonomous decision making.

Supporting autonomous decision making in primary care

Here we seek to describe a deeper understanding of the autonomous positions exhibited by persons when making health care decisions with clinicians whom they know over time and who are aware of the relationships and context within which they live. Using this case study, we

A patient has been registered at a primary care practice for many years and has had a longitudinal relationship with one of the GPs there. He remembers that the GP visited his own mother when she was sick and that on a different occasion, the GP correctly diagnosed one of his children with appendicitis. He attends the surgery because he has received a letter advising him to come in for a review of his hypertension. He would rather not take medication for this. He grew up in a family in which self-sufficiency in all matters, including health was valued above other attributes. He has a friend who developed erectile dysfunction after starting a medication for hypertension. He thinks that having to start any long-term medication is a sign of getting old and of becoming infirm. On the other hand, his wife believes it is important for him to receive treatment and that it is selfish to refuse, given that they have young children. Her own father died of a stroke, which she believes would have been avoidable if he had been prescribed the correct preventative medicines. There are therefore pre-existing if contrasting expectations from the family of how the GP should approach the treatment of hypertension.

The GP spends some time asking after his family and how life is generally. She then goes on to advise him that uncontrolled hypertension increases the risk of cardiovascular disease and recommends that he start treatment. After consideration, he agrees to do this.

consider how these factors may give rise to inherent shortcomings when applying a traditional account of autonomous decision making to a primary care context.

In order to arrive at an autonomous decision, the patient must have access to ‘adequate information’. The notion of ‘adequate information’ carries with it an assumption that information or factual knowledge is absolute and certain. Indeed, this could be argued to be central to the legal notion of informed consent. In contrast, we would assert that knowledge can only ever be partial and is contingent on interpretation and context.³⁴ In the example above, the GP presents information which is true in some senses when she advises our patient to commence treatment in order to lower his risk of heart attack or stroke. It is known that at a population level, the risk of cardiovascular disease is reduced by his lowering blood pressure, although there is uncertainty as to whether this reduction in blood pressure (or, in consequence, cardiovascular risk), will translate to increased longevity for our patient.

The information presented by the GP is not individualised to her patient and she does not consider his context. She has assumed that he has the same priorities as she does and is imparting her knowledge through this lens. Apart from cardiovascular risk, she has not discussed the unintended consequences of treatment – such as the effect on his identity and mood which might result from taking medication; potential adverse effects; or the impact on work. Even the best doctor in the world cannot predict precisely the effect on an individual patient of applying guidelines based on population statistics. It could be argued that the GP is unable to provide information which is truly individualised because of this inherent unpredictability. Of course, the effect of the medication, on both physical and mental well-being influences the likelihood of continuing concordance with treatment. However, for the purpose of this article, we are considering respect for the principle of autonomy as it relates to a discrete interaction rooted in the present.

Information is also interpreted within and influenced by the systems of which we are part. The GP whom our patient sees is the practice lead for hypertension management and for maximising income from the national performance-related pay scheme, which rewards management of chronic disease according to accepted standards. Performing well is both a quality marker and a source of revenue for the practice. The practice has long received communication from external regulators such as the English Care Quality Commission, both

written and verbal, emphasising the importance of being seen to demonstrate high-quality care. ‘High quality care’ has become conflated over time with achievement of specific clinical outcomes and all clinicians working in the practice now accept this paradigm without question, although it has never been formally articulated in this way by members of the team. The culture of an organisation influences how factors such as continuity of care and longitudinal relationships are valued and fostered. For example, the culture of a practice will determine whether everyone in the team is given an equal opportunity to be heard; how the clinicians see their roles (in terms of being limited to a biomedical framework or having more holistic input); and whether longitudinal relationships with patients are valued. This will in turn influence the type of interaction clinicians have with patients. Similarly, the manner in which individuals or groups of clinicians discuss, agree, and adhere to protocols of external guidance has an influence on patient autonomy – in this case, influenced by the interactions with the external bodies described above. A result can be the privileging of safety and extending patient longevity over other considerations, which in turn influences how the data pertaining to hypertension is both interpreted and imparted by the GP.

Closely related to provision of adequate information is the ability of the patient to understand what is said and to demonstrate that they understand it. But this understanding is based on imperfect knowledge, which we describe above as partial. In our example, the patient leaves his GP understanding that taking the anti-hypertensive medication will lower his risk of cardiovascular disease and therefore by extrapolation will increase his life expectancy. As we have seen, the information given is always influenced by the context of the giver and cannot reflect the absolute truth; and therefore, the patient’s understanding of what is said, based on the information given, will also be flawed.

The level of understanding achieved is also related to the capacity of the individual patient and so will not be the same for everyone. Whilst the capacity of persons to understand information about, for example, the nature and purpose of any given intervention is context specific (and indeed there are instruments to assess objectively such a capacity) this is not quite the same thing as our patient achieving a full understanding of the intervention comparable to that of his GP. Indeed, were that the case, the need for medical advisers at all would be rendered somewhat superfluous.

The gap between the two states of understanding could be said to be filled by the trust between doctor and patient, in the presence of a long-term relationship and the doctor keeping her patient’s best interests at heart. The latter of course has a patina of paternalist practice about it. Furthermore, we should distinguish such considerations from the formal assessment of competence or capacity necessary where there is legitimate concern about cognitive function as a result of pathology. One of the

principles in the English *Mental Capacity Act 2005* [there being separate but similar legislation in Scotland] is that capacity in that cognitive sense is always assumed, and only formally assessed where there is clinical, and therefore legitimate, doubt of its presence.³⁵

Next, we consider the notion of freedom to arrive at a personal conclusion. The very existence of free will has been a matter of strenuous debate.³⁶ Nobody lives in a vacuum – we all exist in relation to others and the way in which we understand the world is shaped by the relationships we have with other people. Our patient is also part of their own social and belief systems: his upbringing, his family, his friendship circle, and his relationship with the practice. The uneven power dynamic between practitioner and patient also influences the degree to which patients are able to make autonomous decisions.

Environmental factors can also have an unexpected influence on the information given. For example, if the consultation is undertaken by telephone, perhaps the GP will not pick up on cues which indicate a reluctance on her patient's part to accept medication. If she is running late or is under pressure to meet certain targets, the way in which she presents the information to him may change, with a greater emphasis placed on the benefits of treatment.

When our GP sees the patient, she is suffering from a headache and is hoping that this consultation will be over quickly. She checks his blood pressure and noting it to be high, advises him that the safest option is to start treatment. Normally she would ask about his attitude to taking a regular medication but this time she does not.

His historic relationship with her, reinforced by the small talk at the start of the consultation means that he has confidence in what she says and interprets her meaning to be that it is irresponsible (and dangerous) not to take medication for his high blood pressure. She feels a duty of care towards him but in this interaction, she has privileged his safety over other considerations and has assumed that he is in accordance with her. Although taking a regular medication does not fit into his value system or preferences, he agrees to go along with her advice and leaves feeling that he has made an autonomous decision about his treatment, although this is clearly not the case. This example describes the subjective nature of the way in which autonomous decision making is interpreted in general practice. Apart from the interaction itself, another factor playing into the patient's decision making is his willingness to subordinate his personal preferences to further the wellbeing of his family.

Consider finally a primary care practitioner with knowledge of and a relationship with several members of a family, and a duty of care to all of them. One of the families makes a request for contraceptive treatment. In a traditional model

of autonomous decision making, the interaction between family practitioner and patient is a straightforward account of information exchange, discussion, and a shared therapeutic alliance³⁷ in coming to a contraceptive choice. It is necessarily quite a detailed interaction and may need to be revisited on several occasions before the shared decision is enacted. The notion of the joint decision making between clinician and patient is also a more recent phenomenon, having evolved from the previous medically led and implemented process³⁸ more representative of paternalist practice. However, when considered a little further it is possible to identify other factors that influence the degree of freedom in decision making – such as the views and attitudes of the patient's sexual partner, cultural and religious beliefs of the patient and health care practitioner, and power differentials within social and therapeutic relationships that influence the nature and choice of contraceptive intervention. The freedom to decide or exercise a choice about contraceptive treatment is patently influenced and may even be curtailed. On the other hand, active involvement of the family can be a useful adjunct to an autonomous decision in this sort of case where the index patient welcomes such a contribution – Gilbar has found empirical evidence to support this contention and grounds his findings in a theory of relational autonomy, which has common ground with our case study.³⁹

Implications and concluding remarks

We have explored the widely perceived required conditions for successful autonomous decision making: provision of adequate information, demonstration of understanding and freedom to arrive at a personal conclusion. However, we have seen that in primary care, the information available for decision making is always partial, the freedom of patients to make decisions about their health is curtailed and influenced by contextual forces, and the demonstration of understanding is therefore incomplete.

Seen through the lens of a doctor–patient interaction, autonomy is realised through the choices made available to a patient by the doctor and those entertained by the patient. These choices are profoundly influenced by the contexts of the individuals involved as well as the longitudinal relationship between the protagonists. Autonomy is constrained and liberated by the nature of the interaction where differences in power, the flow of communication between individuals, and organisational and group culture play an important role.⁴⁰

Consultations between clinicians and patients, set in the context of primary and community care, are dynamic and unpredictable. Normative moral theory assumes that applying a set of principles or ideas will clarify the most appropriate course of action – this is especially so with utilitarianism and rule-based ethics.

There is also an underlying assumption that it is possible to separate the actions of individuals from the consequences of their actions, and that by doing so, actions and consequences

can be separately subjected to analytical review; as well, that all the potential consequences of an action can be pre-determined (based on logic and prior experience) and are thus amenable to analysis as a means of guiding the clinician.⁴¹ It can therefore be held that a normative morality which changes little over time may not be responsive to the essential unpredictability and dynamic nature of primary care consultations. Nor does it consider the context and effects of the longitudinal relationship between patient and clinician.

The messy reality of primary care clinical practice therefore sits in contrast with normative ethical theory, which places much value on autonomy and assumes that it is possible for patients to make autonomous decisions, independent of the context in which these decisions are made.

Consultation models extrapolate from this position to privilege shared decision making with the patient, without necessarily scrutinising what is meant by this, nor do they provide an insight into the underlying theoretical perspectives and assumptions that inform their development. The effect of privileging autonomy as it is currently perceived, is that clinicians may simply offer their patients a range of options without any reference to or exploration of either the influences on the patient or the influences on the clinician themselves. It might even be said that the notion that autonomy is possible is constructed, leaving patients with an inadequate foundation on which to base their decisions.

We conclude finally that autonomous decision making is better understood as being relational and contingent on context and thus, most obviously in primary care, diverges from that described in its traditional versions.

When visualising decision making through this relational lens, it is relevant to consider the kinds of dispositions that primary clinicians should seek to hold in promoting autonomous decision making with their patients. We suggest the role of the clinician shifts towards helping their patient understand the different influences on their decision making; whilst also having the self-awareness to understand that their own advice is subject to external influence (such as performance-related payment schemes and regulatory bodies).

As primary care professionals, we need to pose questions to ourselves such as:

what difference would it make to my actions if there were no external targets? or

how much have I (subconsciously) used the power imbalance within the interaction to influence its outcome and if I did, did I do so judiciously?

In addition to making explicit and exploring the influences patients and clinicians bring to bear on the consultation, encouraging a flow of dialogue generates an opportunity to reshape and reframe an understanding, or put another way, to 'make sense', of the world in which we live.

Encouraging such reframing and understanding of the human condition generates the opportunity for growth and agency for patients. It might even be said to support the notion of creation of autonomy advanced by scholars such as Seedhouse.⁴² Promoting a flow of dialogue between clinician and patient is therefore of paramount importance. Perhaps, in practical terms, we need to routinely use circular questions to try to understand the different influences on the patient. For example, a clinician could ask '*what would your wife say if you declined treatment?*' which recognises explicitly the relational component of the decision or how their medical condition influences their sense of identity and purpose.

In order to truly provide patient-centred, relational autonomy, we propose that this should be included in curricula and training programmes for primary care clinicians. Co-creation of meaning between clinician and patient means engaging with a diversity of views as well as contemplating an almost infinite range of paths or choices for the future. The expression of autonomy in such decision making requires clinicians to facilitate discussions whilst encouraging these choices to be those of the patient. This requires clinicians to '*acknowledge and accept that there is inherent risk in individualised relational care*'.⁴³

In conclusion, we endorse a conception of respect for the principle of autonomy that is relational, context specific (in time and space), often limited in terms of 'free will' and which cannot be considered independent of the protagonists involved in the process. In promoting such relational autonomy, clinicians must pay attention to the influences they and their patients bring to bear upon the consultation, invite a dialogical exploration of these influences and choices, encourage a reframing of mutual understandings of our lived experience as humans, and be willing to recognise the inherent risk associated with accepting patient-led decision making. Training should build capability to recognise influences on ourselves and on our patients when making health care-related choices. We need to place more emphasis on our role in clarifying for our patients the different perspectives influencing their decision making.

This position has grown out of our experience and the developing scholarship in primary care ethics. We are conscious that these reflections from the world of primary care sit comfortably with recent theoretical perspectives from philosophy that have softened the sharp edges of traditional individualistic thinking about respect for the principle of autonomy.


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Supplemental material

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