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Rethinking Autonomy and Consent in Healthcare Ethics

Eleanor Milligan and Jennifer Jones

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Abstract

In healthcare ethics, autonomy has arguably become the 'principal principle'. As a principle that can be readily turned into a process, the giving of 'informed consent' by a patient has become the surrogate measure of whether medical interventions are ethically acceptable. While 'informed consent' processes in medical care are presumed to be robust, research confirms that most patients do not adequately understand the medical purpose, limitations or potential ethical implications of the many medical procedures to which they consent. In this chapter, we argue that the founding tenets of autonomy and informed consent which presume people to be detached autonomous individuals who act rationally from self-interest does not authentically capture the essence of human 'being'. Furthermore, such assumptions do not acknowledge the deeply relational and embedded reality of the human condition which inevitably shape decision making. We contend that within healthcare organisations, the current processes of operationalising informed consent predominantly serve legal and administrative needs, while unwittingly disempowering patients, and silencing key aspects of their experience of illness. Rather than rational self-interest, we argue that vulnerability, interdependence and trust lie at the core of ethical decision making in healthcare. Re-framing autonomy in a way that deliberately considers the unique moral frameworks, relationships, and cultures of individuals can provide a more ethically sensitive and respectful basis for decision making in healthcare. As interdependence is an integral consideration in decision making, it must be deliberately acknowledged and incorporated into healthcare practices. Embracing a narrative approach within a shared decision making framework allows the vulnerabilities, fears and aspirations of stakeholders to be heard, creating a more effective and authentic way to meet the ethical goal of respecting those who seek care.

Keywords: autonomy, consent, vulnerability, interdependence, narrative

1. Introduction

1.1. The case of Mr H

Mr H is an 83 year old Australian man who presents to the Emergency Department with a fever and in a confused state having been found wandering the streets of his neighbourhood. Mr H is known to have a pre-existing condition of Chronic Obstructive Airways Disease (COAD), and diabetes which he has been managing adequately with the help of his General Practitioner. Mr H has a 50 year old daughter, K, who lives nearby. She visits him daily, accompanies him to medical appointments, provides him with meals and attends to his cleaning and laundry needs. Mr H also has a 48 year old son, S, who lives overseas in the United Arab Emirates (UAE). Both K and S have an Enduring Power of Attorney for health matters in respect to their father. K has spoken to her brother in recent months about the need to consider alternative supported accommodation for her father as the load she carries, along with caring for family and working is becoming too great. K has experienced mild depression in recent months. S is adamant that, while his father wants to live independently and is able to make decisions for himself, their father should remain living independently. Mr H has always been clear in stating his ongoing desire to remain in his own home for as long as possible.

After admission, Mr H's confusion has been resolved on the treatment of a kidney infection. He is now medically stable although his chronic health conditions are expected to worsen significantly over time and the amount of home care needed is predicted to increase considerably. The attending team arranges a family meeting to discuss discharge planning. K and Mr H attend in person. S attends via telephone from the UAE. Mr H remains adamant that he will return home and is requesting all future care be provided in his home. He does not agree with moving into supported accommodation although the attending team is unanimous in their advice that this is the best option to meet his escalating care needs. Mr H has advised he intends to discharge himself against medical advice even though no plan has been put in place to meet his increasing healthcare needs.

Should Mr H's autonomy override all other considerations when approaching this decision? Whose decision is it anyway? What other considerations are at play? Is individual patient autonomy/choice the best lens through which to view the questions and consequences of attaining the best outcome for Mr H and his family? What is the impact of patient's choice and family conflict on healthcare staff?

In Australia, as in other Western nations, decision making in respect to healthcare matters is founded on the assumption that autonomous individual patients make choices in their best interests in alignment with their own moral frameworks. An individual is regarded as the thinking person who is able to make decisions freely, unencumbered by the needs, desires or perspectives of others. These beliefs have their origins in the work of Immanuel Kant who argued that respect for autonomy flows from *'the recognition that all persons have unconditional worth and the capacity to determine their own moral destiny'* [1]. Over many decades, our collective expectations have evolved and autonomy is now primarily regarded as individual independence.

One of the ways healthcare organisations have operationalized respect for this principle is through the administrative process of garnering the ‘informed consent’ from a patient prior to any medical intervention. The completion of an appropriately signed informed consent form, or documented discussion, is offered as assurance that any decisions or interventions undertaken, or rejected in the case of Mr H, are understood, in alignment with the patient's wishes and are ethically sound. While ‘informed consent’ processes in medical care are presumed to be effective, research confirms that most patients do not adequately understand the clinical purpose or personal ramifications of many interventions. They often do not understand the limitations, risks or potential ethical implications of the interventions consented to, hence, the assumption that patient ‘consent’ or acquiescence equates to ethically sound autonomous and informed choice should be challenged. Consequently, the basis on which informed consent processes have been founded within healthcare settings demands rethinking.

The reasons why informed consent processes have failed to substantively promote patient autonomy in healthcare are multiple. Flawed modernist conceptions of autonomy falsely elevate individualism at the expense of considering important relational considerations, the medico-legal focus of healthcare organisations can wrongly equate the minimum standard of disclosure to the higher ethical standard of respect and understanding, while environmental and educational barriers such as limited time for discussion all combine to undermine informed consent. At the core of these failures is the loss of attention to the individual patient and their vulnerability, in addition to a minimizing of the interdependent nature of healthcare.

This chapter, drawing on the case study above, challenges the dominant understandings of autonomy. It also questions how autonomy is presumed to be embedded and respected in healthcare settings. Finally, it sets the foundation for an alternative, and richer understanding of individual moral frameworks at the core of effective therapeutic relationships. With an appreciation of the vulnerability which is at the heart of the healthcare encounter, this chapter provides a way to approach respectful communication in healthcare, to understand how individuals make ethical choices, and to accept how interdependence, rather than independence, rightfully shapes the ethical tone of encounters in healthcare.

2. The rise of autonomy in medical ethics

The word autonomy is derived from the Greek words ‘autos’, meaning ‘self’ and ‘nomos’, meaning ‘governance’ or ‘rule’. It is on these more individualistic understandings that informed consent procedures in the healthcare setting are premised. Manson and O’Neil [2] explain,

*‘It is easy to see why those who see autonomy as a matter of individual independence link it so closely to informed consent: informed consent procedures protect individual choice, and with it individual independence, hence individual autonomy. So if we can show that individual autonomy is a fundamental value—better still **the** fundamental value—and that it can best be protected and implemented by informed consent requirements, it may*

prove possible to justify informed consent procedures as required if we are to respect autonomy' (p. 18–19).

The desire that a person should act voluntarily from a position of knowledge and understanding, to give their voluntary 'informed consent' to any medical intervention, and be supported in their capacity to exercise free will without coercion, is widely valued in Western society. Since its inception with respect to research participants outlined in the Nuremberg Code in 1947, and reinforced in subsequent versions of the Declaration of Helsinki, the specific requirement that practitioners seek patient consent has extended to clinical care. Over the past four decades, seeking consent from patients prior to medical treatment has become ingrained in health care practice [1] that it is now '*so well entrenched that [it's] presence, indeed [it's] necessity, and justification are rarely questioned*'ⁱ (p. 2).

However, there is growing evidence that 'informed consent' protocols as applied in healthcare have achieved limited practical success to date^{ii, iii, iv, v}. Understanding the gap between the ethical intention and practical reality of informed consent requires us to revisit the philosophical origins of autonomy. The detached autonomous, individualistic 'I', who will rationally consider their accessible options and give an unencumbered and reasoned response to the question 'what ought I do', is largely a product of modernist conceptions of the self. While this concept of the 'autonomous self' permeates the bioethical discourse, as Isaacs [3] notes, '*this self is not a human self*' (p. 3); it does not reflect the lived reality of human 'being' or enhance understandings of how deeply embedded decisions are interpreted and made. People do not ignore personal sentiments in moral reasoning, nor are they detached from sentimental consequences [4]. Human beings are intentionally partial to family and friends and have mutual obligations of care, responsibility, trust and affection. Hence, while individuals may consider themselves to be rational and independent to a degree, they are unquestionably and primarily embedded and embodied beings with particular roles and responsibilities that may present non-negotiable constraints on their ability to act in a purely individualistic or rationally considered way. Social relationships, contexts and practices are not separate from autonomy or individuality. Hence, embracing the social context and accepting interdependence are integral to realising self-governance.

Other assumptions embedded within narrowly defined biomedical applications of the principle of autonomy are [5]:

- That the person making the decision, and not the community to which they belong, are the final arbiter of the integrity of the decision made.
- That real access to a variety of options actually exists, and can be readily accessed.
- That relationships with others are supportive, both psychologically and socially, and there is no consequence of abandonment or retaliation if a choice is made that others, upon whom the person may depend, oppose.

In the case of Mr H, the community at large are undoubtedly affected by his insistence that he remain at home. Such a decision is likely to require the provision of expensive individualised in-home services paid for from the communally funded healthcare system. Directing funds

into such care, which could be provided more economically in a shared supported care environment, may divert scarce resources from other healthcare areas where more benefit could be gained for more people. Cost must also be recognised as an ethical issue [6], hence, the decision to insist upon a certain type of care cannot be made by the patient alone. According to Bailly [6] individuals do not have '*the moral or legal right to make unlimited demands...to pursue their own idiosyncratic goals*'. Health practitioners, as gatekeepers to collective resources, also have a competing moral obligation to ensure limited collective resources are spent in the most effective way to the benefit of the community more generally.

Family members arguably have duties to their ill relative; however, a relative cannot dictate, demand or impose how these presumed duties are met. In the case of Mr H, his decision to return home when he is clearly unable to attend to his own activities of daily living place a burden on K that she may be unable to fulfil. Should Mr H remain at home and K feel compelled to meet his escalating care needs, she may become further distressed and unwell. Hence, the emotional and health costs of carer burnout for K are further considerations that may create future burden on the healthcare system, and impact on K's quality of life [7]. Mr H's decision to refuse supported accommodation is likely to create friction between his son and daughter, and may undermine the psychological and social support he receives. Mr H's decision to reject the advice of his attending team may also impact negatively upon the therapeutic relationship and his ability to seek advice and care from clinicians familiar with his overall health and wellbeing. Considering all of these competing interests it is not surprising that Manson and O'Neil [2] conclude,

'Individual autonomy cannot be the sole principle of medical or research ethics, and consent requirements that protect individual autonomy cannot be the sole criterion of ethically acceptable action' (p. 19).

3. The administrative and legal focus: informed consent processes and the undermining of patient autonomy

Philosophically, problems with the underlying assumptions about autonomy can derail getting to the core meanings and ethical interpretations being made by patients and practitioners alike. However, there are also administrative and legal sequelae. As the principle of respect for autonomy has become synonymous with the administrative process of garnering 'consent', informed consent processes now serve a multitude of administrative and legal (rather than ethical) purposes. According to Manson [8], these purposes include:

- Demonstrating 'proof' of ethical practice, as patient 'rights' have been incorporated into verifiable administrative processes. In some interventions, for example, there is an administrative requirement that consent forms are signed, thus ethical legitimisation is conferred to existing medical practices.
- Providing a defensive legal document lending protection to medical practitioners against potential legal recourse.

- Distancing medical care from the widely criticised paternalistic practices of the past by positioning the decisional capacity as resting solely with the patient.

Despite a wide body of social research flagging patient vulnerability and unequal power dynamics as factors which heavily compromise autonomy and weaken the capacity to freely exercise agency [9 (p. 115), 10, 11] participation alone is persistently accepted as evidence of ethically sensitive care. As any intervention taken is consensual, the belief appears to prevail that *'no injury can be done where the subject is willing'* [2] (p. 3). However, participation or willingness alone does not automatically mean that such participation is informed, nor does participation necessarily safeguard ethical acceptability, even if it does meet the minimal legal standards. Choices made from a narrow field of choices made available may not represent the most desired choice from the patients' perspective. The inevitable narrowing of choices in institutionalized healthcare may therefore conceal deeper injustices leaving them hidden and unchallenged [4, 9, 10].

The strong legal bias that informs institutionally developed consent protocols may have focused attention too heavily on facilitating the practitioner 'getting' consent, while inadequate attention has been given to supporting the full and embedded understanding of the patient 'giving' consent. Critical questions of who informs, what they inform, and for whose benefit the information disclosed can further undermine consent. While we may accept, as Beauchamp and Childress [1] do, that because *'actions are never fully informed, voluntary or autonomous, it does not follow that they are never adequately informed, voluntary or autonomous'* (p. 88), we ought to remain vigilant to institutional practices which inhibit discussion of the ethical implications of medical care. The ethical standard of understood consent cannot be presumed to be inherent within the minimal legal criteria for informed consent as the legal bias which permeates organisational practice can engulf the more subtle moral or ethical questions [11]. Indeed some commentators openly describe existing informed consent protocols as empty bureaucratic rituals [12], the main purpose of which is to provide a defensive legal document or form of insurance against malpractice suits, while paying superficial concern to the moral dimensions of care. When the motivation to procure consent becomes a matter of fulfilling a legal obligation or averting litigation, the clash of motivation between those seeking consent and those giving it potentially creates a conflict of interest that further widens the existing divide between patient, practitioner and the organisation in which they meet.

Some real practical problems follow in trying to actualise informed consent in the contemporary healthcare environment. Entrenched institutional pathways such as the routinised nature of care with predetermined, expected outcomes can obscure 'choice'. Sometimes lack of genuine access to alternative options can delimit which choices are permissible. Limited time for consultations can prevent the formation of effective communication partnerships between the patient and their family, while poor access to adequate education and knowledge building converge to create a situation in which a patient's individual agency can become significantly compromised.

Against this backdrop it is perhaps not surprising that low levels of informed consent persist across many fields of medical intervention. Disturbingly low figures in meeting the ethical requirements of informed consent have been reported at 0.5% success for *'complex'* decisions,

defined as having extensive effect on the patient with uncertain and multiple outcomes, and reaching a mere 26% success for simple decisions where the effect is minimal and the outcomes are clear and singular [13]. Such poor success in achieving informed consent within medical care generally exposes the failure of current approaches. Although the accepted protocols may meet the minimum legal or administrative requirements, they commonly struggle to fulfil their ethical purpose of preserving patient autonomy and empowering the patient with the right to intentionally embrace or reject the interventions [11, 14–16].

Collectively, these administrative and legal considerations can act to undermine patient understanding and choice. With respect to Mr H, his family and attending team—if the team simply takes Mr H at his word, the minimal legal and administrative requirements can be fulfilled by explaining the risks of discharge against medical advice and documenting this in Mr H's chart. As an autonomous adult with capacity to decide, Mr H has the right to make decisions that may not be in his best medical interests as defined by others. He can also make decisions that create burden for others, for example, a burden on his daughter K and on the shared healthcare resources of the district. Should Mr H deteriorate further at home due to inadequate care, the cost of his next admission is likely to escalate as the acuity of his medical needs increase [17, 18]. The team may feel they have respected the autonomy of Mr H, and they can confidently watch Mr H go home to let the inevitable decline unfold. As they have no direct duty of care to K or S, they need not consider the impact beyond Mr H. They have fulfilled their legal and administrative requirements. Yet, this outcome may not be seen as satisfactory from an ethical perspective as the harms that will inevitably flow to many stakeholders from such a decision have arguably not been thoroughly considered. This outcome also denies Mr H the chance to begin a dialogue about end-of-life planning, a decision which may ultimately place a higher burden on his family and the healthcare service.

4. A different view: vulnerability, interdependence and narrative as integral to ethical healthcare

The practical question of whether Mr H's outcome could be different if we took a different view of autonomy begs consideration. If we embraced this different view and allowed it to permeate our administrative and educational processes in healthcare, how might patient, carer and health practitioner relationships and decisions be affected?

We propose that there is a deeper, more realistic way of thinking about human beings, in particular vulnerable human beings, in the context of healthcare. Philosophers such as Taylor [19], and many feminist scholars [20–23] have written extensively outlining such an alternate reframing of the self as deeply relational and socially embedded. Recognising that the '*individual is whole only in a world of others*' [24] the dominant conception of autonomy as overly individualistic, atomistic and detached is rejected.

Hoffmaster [25] further considers the consequences of assuming human beings are first and foremost detached and rational creatures.

'Human beings are rational, but human beings also have bodies and because they have bodies, they are vulnerable. In fact vulnerability is an even more basic feature of our human constitution than rationality, because while all human beings are vulnerable, not all are rational or even possess the potential to become rational...it is our very vulnerability that creates the need for morality...vulnerability marks the limits of individualism...' (p. 43).

Acknowledging patient vulnerability creates the ethical imperative to care. It is arguably vulnerability rather than patient autonomy that shapes the moral core of clinical practice [26–29]. In the clinical setting, vulnerability and interdependence defines the patient experience creating a moral imperative for trustworthy others to care. Together vulnerability, interdependence and trust form the moral essence of healthcare.

As human beings are primarily relational beings, our experience is principally defined by social connectedness embedded in relationships and power dynamics. Each 'autonomous' act has repercussions beyond the immediate decision maker. Additionally, broader social contexts and practices may support or inhibit individual choice. Relationship and interdependence are undeniably key elements of autonomy, hence acknowledging, incorporating and respecting these must form a central foundation of healthcare delivery. Current informed consent protocols distance these insights preferring instead a model which seeks to de-contextualise and detach ethical deliberations, then re-insert a solution as if it were independent of the uncertainty and complexity which created it.

Taylor [19] maintains that the human self is not primarily a rational thinker, but rather an actor or doer, projected into a complex world in which they seek to make and find meaning. Capable of interpreting their world and their place in it, human beings are also capable of creating and re-creating, interpreting and re-interpreting themselves and others. Therefore, a unique aspect of being human is the capacity to change, grow and become when given the support and opportunity to do so. An individual's moral knowledge is not static but constantly evolving and subjectively interpreted. If we see the fundamental purpose of informed consent as a practical exercise of ensuring the needs, interests and aspirations of all participants are respected, then consent must be founded on shared appreciation of people as related, dialogical, and interpretative beings who are embedded in multiple contexts of history, culture, language, relationships, biology, time and spiritual horizons entrenched in complex social dynamics. Each of these layers informs the meaning of illness and shapes the choices made. Appreciation for the complexity of meaning making must therefore be actively sought in the healthcare environment.

With this view of the self at the centre of human interactions, a narrative approach to decision making in healthcare enables us to enter into, and appreciate, each other's understandings with conversation and dialogue providing an appropriate entry portal into the world of another's experience and knowledge. Indeed, Taylor [19] contends, *'the nature of our language and the fundamental dependence of our thought on language makes interlocution in one or other of these forms inescapable for us'* (p. 38). What is vitally important is that the conversation begins and ends within the deeply contextualized relationships between staff, patients and the organization.

4.1. The role of narrative in healthcare

In considering how human beings construct meaning from the experiences that weave the fabric of their everyday lives, Bruner makes the point, '*we organise our experience and our memory of human happenings mainly in the form of narrative—stories, excuses, myths, reasons for doing and not doing, and so on*' [30] (p. 4).

Narrative invites us to enter into the being and becoming of others, to appreciate their embodied and embedded experiences. It opens the possibility of sharing, understanding and appreciation of the complex and unique lived reality and plural moral frameworks that are unique to each person. It further enables the expression of experiences of loss, suffering, or oppression to be voiced, especially by those who may feel disempowered or silenced. Finally, narrative opens up new meanings, new possibilities and new sensitivities for collective and individual moral insight and growth.

Due to the dialogical nature of being human, narrative is widely recognised as significant in enhancing ethical understandings [31–35]. By voicing our experiences in dialogue with another, our shared common understandings are deepened which in turn opens each person to the rich complexities of each other's lives. Through this deepening of shared understandings and ethical orientations/motivations, our individual and shared ethical judgments can be better informed. Thus narrative and dialogue are pivotal in shaping not just the ethical agenda, but also the process of *fully* informed decision making [36, 37]. Kearney [38] notes,

Far from being ethically neutral, each story seeks to persuade us one way or another about the evaluative character of its actors and their actions... stories alter our lives as we return from text to action. Each story is loaded (p. 55–56).

According to Canadian medical sociologist Arthur Frank [39], narrative has a further role to play in illness. Narratives provide us with the means for not only making sense of the disruption that illness has wrought on our lives but also is the means by which we are able map and re-map the future direction of our life. Stories '*repair the damage that illness has done to the ill person's sense of where she [sic] is in life, and where she [sic] may be going*' (p. 53). As the means by which both the path and the destination can be mapped, *fully* informed consent must therefore take a narrative form if the differing perspectives of each of the characters who make up any one life story are to be accounted for. Frank further contends that illness narratives are shaped around one of three narrative forms: the restitution narrative in which the ill person seeks to return to a pre-ill state; the chaos narrative in which the ill person cannot imagine life improving; and the quest narrative in which the suffering is met head on—the illness (and accompanying suffering) is accepted and is used for improvement. Each person's narrative is deeply embedded in another's. Therefore, a change in the shape of one's life narrative inevitably impacts on both the life and narrative of each relational 'other'. It is this truth of human interaction that compels us to rethink autonomy and place relationship at its core.

If Mr H's story was pieced together in the coherent whole from his perspective, what might his children and the attending team come to understand? Might his identity be strongly interlinked with being in his house where he keeps the memories of his wife and their life together alive? Might the routines he has established over many years be a strong comfort to

him? If K could voice her story might she express signs of carer fatigue and need opportunities for respite, or might she reveal her sense of life purpose is in tension with her father, brother, husband and children? Could S's story reveal something other than being autocratic and distant from the day to day realities of his father? Might he have some legitimate concerns for his father being moved not previously taken into account? Might the deeper understandings of the attending team resulting from being engaged in many similar stories of people in Mr H's position with his condition offer insights for Mr H and his children? Voicing and listening attentively together to these diverse narratives about Mr H's current and future life may build up a new narrative. Such a new narrative might better integrate and unify the values each viewpoint is motivated by and may enable the creation of a story all can find morally beautiful:

Giving voice to the moral beauty we recognise in others is a loving and caring act that is not without its influence on our sense of self. The self always exists in relation to others and is authored in conversations with many others. The self flourishes in a community of dialoguers giving voice to moral beauty [40].

Finally, as Connelly [41] notes, creating strong therapeutic relationships must begin with 'mindfulness', an openness to help the patient tell their story and a commitment to value this unique story when it is told.

'Physicians must be able to help the patient tell the story that is most important, meaningful and descriptive of the situation. If the patients' narrative is not heard fully, the possibility of diagnostic and therapeutic error increases, the likelihood of personal connections resulting from a shared experience diminishes, empathic opportunities are missed and patients may not feel understood or cared for' (p. 84).

5. Education and communication

The current focus on 'getting' informed consent to meet legal and administrative requirements has fuelled approaches to patient education in healthcare that can be superficial and often woefully inadequate. Commonly, research indicates that educational materials aimed at assisting patients in giving informed consent frequently omit topics of relevance to patients, overestimates the usefulness and benefits of intervention, and often contain inaccurate, misleading, or incomplete information [42–48]. Coulter's [44] review of informed consent practices found widespread failure to provide accurate and balanced information of relevance to patients entrenched across many fields of medical care. This research concluded:

'Current information materials for patients omit relevant data, fail to give a balanced view of the effectiveness of different treatments and ignore uncertainties... the most common fault [of educational material] was to give an overoptimistic view, emphasising the benefits and glossing over the risks and side effects' [44] (p. 318).

As a basis for informed decision making, promoting patient understanding is critical to respecting their choices. When sound understanding is achieved within a strong therapeutic partnership of mutual contribution and respect, research shows positive outcomes for patients

and practitioners including active acceptance of outcomes (positive and negative), increased satisfaction and more stable decisions, higher compliance with treatment, lower instances of litigation and fewer ongoing referrals [49–52]. Effective communication and education are therefore critical in building enduring and effective therapeutic alliances.

Within a framework of relationally aware, socially contextualized and interdependent understandings of autonomy and informed consent, practical problems of how to inform (in addition to ‘what’ to inform) arise. The further question of how to translate information to understanding that has meaning for the person making the decision must also be considered. This is essentially a process of learning and education. The importance of incorporating successful teaching, learning and communication strategies into strengthening informed consent procedures is a practical route to explore. Such an educational stance in the clinic requires explicit recognition of the multiple underlying social, personal, institutional and philosophical constraints that impinge upon the practical realisation of autonomy, consent and choice.

5.1. Communication: commitments and barriers

‘Strangers taking care of strangers can come to be as pathological a factor in certain situations as sepsis’ [12] (p. 95).

Dialogue and communication lie at the ethical core of human interactions in healthcare. The ability of patients and physicians to communicate effectively is an essential element of medical care, as it is through these dialogical encounters that mutual appreciation and understanding can emerge. Consequently, barriers to effective communication contribute significantly to the ethical failures observed both in the existing literature as they render patients and practitioners vulnerable. Time pressures, under-resourcing, inadequate support and/or training of staff and, perhaps, organisational, institutional and gendered hierarchies of power in which the patient-clinician encounter is entrenched can all significantly undermine effective communication.

While it is generally acknowledged that effective communication lies at the ethical core of clinical encounters, research into communication patterns between healthcare providers and patients predominantly paints a bleak picture [53]. Additionally, the well catalogued tendency to position ethical dialogue and deliberation within carefully demarcated ‘dilemmas’ or ‘headliner quandaries’ [54] has arguably narrowed our view of what constitutes an ‘ethical’ conversation. In fact, every encounter is an ethical one, premised on vulnerability, interdependence and trust, on the ‘micro-ethical’ [55] or underlying ‘moral sensibilities’ [56] of everyday practice, injustices, and relationships. Komesaroff [55] observes, from his perspective as a physician, that ethics not a technical expert discussion, but rather, ethics is ‘*what happens between every patient and every doctor everyday*’ (p. 68). Komesaroff [55] further notes that ‘*the vast majority of clinical decisions are taken in an ethical environment in the absence of any obvious dilemma*’ (p. 67). The educational and professional conditioning of practitioners to regard the ethical within a limited ‘dilemma’ or ‘quandary’ framework ultimately impoverishes their human understandings and thus fails to equip them for the ongoing process of guiding morally sensitive interactions. When ethical debate and education focuses on such remote or extreme examples,

an insidious consequence is that the morality of the commonplace—which is the heart of the ethical—becomes marginalized. Kass [56] explains:

'The use of surrogate wombs or the definition of death or guidelines for terminating life sustaining treatment captures most of the attention- not surprisingly—but the morality of ordinary practice is largely ignored. Yet every encounter is an ethical encounter, an occasion for the practice and cultivation of virtue and respect, and between doctors and patients for the exercise of responsibility and trust on both sides. How do physicians speak to patients? Do they have reasonable expectations of their physicians? How do we, individually and culturally, stand with respect to rearing children, sharing intimacies, revering life, facing death? In the absence of attention to these more fundamental and pervasive moral postures and practices, is it reasonable to expect that an ethics for the extreme cases will be sensibly worked out even in theory, let alone be successful when 'applied' to practice?' (p. 2).

Thus, there is a strong need for practitioner ethics education at every level: graduate; undergraduate and ongoing specialist training to be 're-humanised'. Such re-humanisation must prepare practitioners with the necessary hermeneutical insights and sensitivities to become responsive ethical partners and advocates attuned to the unique everyday moral sensibilities and experiences of their patients. In essence, healthcare ethics must be taught as a transformative, relational, engaged and fundamentally human endeavour. It must be taught as a discipline that raises sensitivity to the vulnerable, instils a broader view of the sources of suffering and harm experienced by patients, and a self-awareness of one's own values and beliefs and how they impact interactions with others.

The 'medical humanities' within healthcare ethics education provides some practical leadership in enhancing practitioners' humanistic and ethical understandings of themselves and their patients. Similarly grounded in a hermeneutical view of the ethical, the medical humanities invite exploration of individual illness experiences through creative works such as literature, poetry, music, biography and art. Thus, we are invited to consider the unique experience of each person, as opposed to viewing the ethical response in terms of '*general principles and typical patients*' [57] (p. 127).

The goal of patient self-determination permeates healthcare rhetoric. For the most part, patients are known to welcome their shared decision making role [49, 58–68]. Embracing 'patientcentred' care, and shared decision making, better supports patient autonomy and is also regarded as a more appropriate and respectful basis from which to form strong therapeutic partnerships. While there is no definitive definition of shared decision making, it is described as an intentional mode of patient/practitioner interaction defined by a partnership of mutual respect, of equally valuing patient preferences, of discussing all options, benefits and risks, of facilitating appropriate education, and of negotiation, deliberation and seeking of mutual agreement on healthcare decisions [69].

The adoption of shared decision making within a patient-centred model of care has many positive health outcomes such as reducing excessive diagnostic testing and ongoing referrals, lowering the incidence of malpractice suits, reducing anxiety, increasing patient adherence to

treatment regimes, improving health literacy of patients and generally improving the health status of individuals [49–51, 70]. Such positive outcomes may be directly attributable to patient perceptions of being included as a full participant [71] in the clinical encounter rather than as a mere passive recipient of treatment or imposed decision. It also has an ethical impact by acknowledging the patient's contribution and expert knowledge.

6. Conclusion

Respect for autonomy as constructed in dominant accounts within bioethics and implemented through informed consent processes in healthcare has failed to deliver on its goal of valuing individuals and promoting individual choice. The legal and administrative processes of garnering 'informed consent' have arguably marginalized patients and silenced key elements of their experiences and goals. As interconnection, relationship, vulnerability and trust are the core elements of human interaction and understanding in healthcare these elements, rather than detached individual choice, must form the basis of practitioner-patient interactions in healthcare. This can be achieved by embracing a narrative approach to therapeutic relationships which enable each stakeholder to be heard, to build shared understanding and to navigate the path to ethical care which respects the embedded and unique moral framework and illness experience of each person. This approach opens access to a richer and more realistic account of autonomy.

Author details

Eleanor Milligan^{1*} and Jennifer Jones²

*Address all correspondence to: e.milligan@griffith.edu.au

1 Griffith University School of Medicine, Queensland, Australia

2 Princess Alexandra Hospital, Brisbane, Australia

References

- [1] Beauchamp T, Childress J. Principles of biomedical ethics. 5th ed. New York: Oxford University Press; 2001.
- [2] Manson NC, O'Neill O. Rethinking informed consent in bioethics. Cambridge: Cambridge University Press; 2007.

- [3] Isaacs P. *Ontology, narrative and ethical engagement*. In *Confessions: Confounding Narrative and Ethics*, 2010. Edited by Eleanor Milligan and Emma Woodley. Newcastle upon Tyne: Cambridge Scholars Publishing; 2010.
- [4] Sherwin S. *No longer patient. Feminist ethics and health care*. Philadelphia: Temple University Press; 1992.
- [5] Oshana MAL. The autonomy bogeyman. *Journal of Value Inquiry* 2001;35:209.
- [6] Bailey MA. Utility, autonomy, and cost in end-of-life care. *The Journal of Law, Medicine and Ethics* 2011;39:172–82.
- [7] Kasuya R, Polgar-Bailey P, Takeuchi R. Caregiver burden and burnout: a guide for primary care physicians. *Postgraduate Medicine* 2000;108:119.
- [8] Manson NC. Consent and informed consent. In: Ashcroft RE, Draper H, McMillan JR (Eds.) *Principles of health care ethics*. 2nd ed. New York: John Wiley & Sons Ltd; 2007.
- [9] Sherwin S. Diagnosis difference: the moral authority of medicine. *Hypatia* 2001;16:172.
- [10] Milligan, E. *The ethics of consent and choice in prenatal screening*. Newcastle upon Tyne: Cambridge Scholars Publishing; 2011.
- [11] Wear S. *Informed consent: patient autonomy and clinician beneficence within health care*. 2nd ed. Washington D.C.: Georgetown University Press; 1998.
- [12] Wear S. *Informed consent: patient autonomy and clinician beneficence within health care*. 2nd ed. Washington D.C: Georgetown University Press; 1998.
- [13] Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice. Time to get back to basics. *The Journal of the American Medical Association* 1999;282:2313–20.
- [14] Braddock CH. Factors that predict better informed consent. *Journal of Clinical Ethics* 2002;13:344.
- [15] Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice. Time to get back to basics. *The Journal of the American Medical Association* 1999;282:2313–20.
- [16] Bottrell M, Alpert H, Fischbach R, Emanuel L. Hospital informed consent for procedure forms. *Archives of Surgery* 2000;135:26.
- [17] Chan WC, Jackson G, Winnard D, Anderson P. Healthcare services funded by Counties Manukau District Health Board for people in the last year of life. *The New Zealand Medical Journal (Online)* 2011;124:40–51.
- [18] Garden G, Green S, Pieniak S, Gladman J. The Bromhead Care Home Service: the impact of a service for care home residents with dementia on hospital admission and dying in preferred place of care. *Clinical Medicine* 2016;16:114–8.

- [19] Taylor C. *Sources of the self*. Cambridge: Harvard University Press; 1989.
- [20] Friedman M. Autonomy and social relationships. Rethinking the feminist critique. In: Meyers DT (Ed.) *Feminists rethink the self*. Oxford: Westview Press; 1997.
- [21] Donchin A. Understanding autonomy relationally: toward a reconfiguration of bioethical principles. *Journal of Medicine and Philosophy* 2001;26:365–86.
- [22] Dodds S. Choice and control in feminist bioethics. In: CMNS (Ed.) *Relational autonomy*. New York: Oxford University Press; 2000, pp. 213–35.
- [23] Sherwin S. *The politics of women's health: exploring agency and autonomy*. The Feminist Health Care Ethics Research Network. Philadelphia: Temple University Press; 1998.
- [24] Cassell, E. Recognizing Suffering. *The Hastings Center Report*. 1991; 21.3, pp 24–31.
- [25] Hoffmaster B. What does vulnerability mean? *The Hastings Center Report*. 2006;36:38.
- [26] Lanoix M. The ethics of imperfect cures: models of service delivery and patient vulnerability. *Journal of Medical Ethics* 2013;39:690.
- [27] Martin AK, Tavaglione N, Hurst S. Resolving the conflict: clarifying ‘vulnerability’ in health care ethics. *Kennedy Institute of Ethics Journal* 2014;24:51–72.
- [28] Hurst SA. Vulnerability in research and health care; describing the elephant in the room? *Bioethics* 2008;22:191–202.
- [29] Tavaglione N, Martin AK, Mezger N, et al. Fleshing out vulnerability. *Bioethics* 2015;29:98–107.
- [30] Bruner J. The narrative construction of reality. *Critical Inquiry* 1991;18:1–21.
- [31] Walker MU. Keeping moral space open: new images of ethics consulting. *The Hastings Centre Report*. 1993;23:33–40.
- [32] Walker MU. *Moral understandings: a feminist study in ethics*. London: Routledge; 1998.
- [33] Tomlinson T. Perplexed about narrative ethics. In: Lindeman-Nelson J (Ed.) *Stories and their limits*. New York: Routledge; 1997.
- [34] Brody H. “My story is broken can you help me fix it?” Medical ethics and the joint construction of narrative. In: Fulford KWM, Dickenson DL, Murray TH (Eds.) *Healthcare ethics and human values: an introductory text with readings and case studies*. Malden, Massachusetts: Blackwell Publishers Ltd.; 2002.
- [35] McMillan J, Gillett G. Consent as empowerment: the role of postmodern and narrative ethics. In: Fulford KWM, Dickenson DL, Murray TH (Eds.) *Healthcare ethics and human values: an introductory text with readings and case studies*. Malden, Massachusetts: Blackwell Publishers Ltd.; 2002.

- [36] Taylor C. *Sources of the self*. Cambridge: Harvard University Press; 1989.
- [37] Widdershoven GAM, Smit MJ. Ethics and narratives. In: Josselson R (Ed.) *Ethics and process in the narrative study of lives*. Thousand Oaks: Sage Publications; 1996.
- [38] Kearney R. *On stories*. London: Routledge; 2002.
- [39] Frank A. *The wounded storyteller: body, illness and ethics*. Chicago: University of Chicago Press; 1995.
- [40] Hancock DW. *An exploration of the virtues project: ontological, educational and cross-cultural inquiries into a moral education program within a Mongolian school*. Australia: Queensland University of Technology; 2015.
- [41] Connelly J. Narrative possibilities. Using mindfulness in clinical practice. *Biology and Medicine* 2005;48:84–94.
- [42] Coulter A. Evidence based patient information. *British Medical Journal* 1998;317:225–6.
- [43] Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *British Medical Journal* 1999;318:318–22.
- [44] Coulter, A What do patients want from high quality general practice and how we involve them in improvement? *British Journal of General Practice* 2002; 52 (Suppl); S22–S26.
- [45] Lawson KL. Expectations of the parenting experience and willingness to consider selective termination for Down syndrome. *Journal of Reproductive and Infant Psychology* 2006;24:43.
- [46] Williams C, Alderson P, Farsides B. What constitutes ‘balanced information in the practitioners’ portrayal of Down's syndrome? *Midwifery* 2002;18:230–7.
- [47] Bramwell R, Carter D. An exploration of midwives and obstetricians knowledge of genetic screening in pregnancy and their perception of appropriate counselling. *Midwifery* 2001;17:133–41.
- [48] Burkell J, Campbell GD. “What does this mean?” How web-based consumer health information fails to support information seeking in the pursuit of informed consent for screening test decisions. *Journal of the Medical Library Association* 2005;93:363.
- [49] Stewart M, Belle-Brown J, Donner A, et al. The impact of patient—centred care on outcomes. *The Journal of Family Practice* 2000;49:796–804.
- [50] Stewart M. Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal* 1995;152:1423–33.
- [51] Levinson W, Roter DL, Mullooly JP, Frankel RM. Physician-patient communication: the relationship with malpractice claims among primary care physicians and surgeons. *The Journal of the American Medical Association* 1997;277:553–9.

- [52] Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. *Patient Education and Counselling* 2003;50:323–9.
- [53] Braddock CH. Factors that predict better informed consent. *Journal of Clinical Ethics* 2002;13:344.
- [54] Liaschenko J, Oguz NY, Brunnquell D. Critique of the “tragic case” method in ethics education. *Journal of Medical Ethics* 2006;32:672–7.
- [55] Komesaroff, P. From bioethics to microethics: ethical debate and clinical medicine. In Komesaroff, P.A. (Ed.) *Troubled bodies: critical perspectives on postmodernism, medical ethics, and the body*, Melbourne: Melbourne University Press.
- [56] Kass LR. *Life, liberty and the defense of dignity. The challenge for bioethics*. San Francisco: Encounter Books; 2002.
- [57] Begley, A. Creative approaches to ethics: prose, poetry and dialogue. In Tschudin, V. (Ed.) *Approaches to ethics: nursing beyond boundaries*. London: Elsevier Science, 2003.
- [58] Godolphin W, Towle A, McKendry R. Challenges in family practice related to informed and shared decision-making: a survey of preceptors of medical students. *Journal of Applied Mathematics and Computing* 2001;165:434–8.
- [59] Bub B. The Patient's lament: hidden key to effective communication: how to recognise and transform. *British Medical Journal* 2004;30:63–9.
- [60] Fisher B, Dixon A, Honeyman A. Informed patients, reformed clinicians. *Journal of the Royal Society of Medicine [NLM-MEDLINE]* 2005;98:530.
- [61] Stewart M, Belle-Brown J, Weston W, McWhinney I, McWilliam C, Freeman T. *Patient-centred medicine: transforming the clinical method*. 2nd ed. Oxon: Radcliffe Medical Press; 2003.
- [62] Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *British Medical Journal* 1999;319:766–71.
- [63] Weston W, Belle-Brown J. The importance of patients beliefs. In: Stewart M, Roter D (Eds.) *Communicating with medical patients*. Newbury Park: Sage Publications; 1989.
- [64] Weston W. Informed and shared decision making: the crux of patient centred care. *Canadian Medical Association Journal* 2001;165:438–9.
- [65] Elwyn G, Edwards A, Kinnersley P. Shared decision making in primary care: the neglected second half of the consultation. *British Journal of General Practice* 1999;49:477–82.
- [66] Say R, Thomson R. The importance of patient preferences in treatment decisions-challenges for doctors. *British Medical Journal* 2003;327:542.

- [67] Little P, Everitt H, Williamson I, Warner G, al e. Preferences of patients for patient centered approach to consultation in primary care: observational study. *British Medical Journal* 2001;322:468.
- [68] Coulter A, Magee H. *The European patient of the future*. Maidenhead: Open University Press; 2003.
- [69] Makoul G, Clayman M. An integrative model of shared decision making in medical encounters. *Patient Education and Counseling* 2006;60:301–12.
- [70] Braddock CH. The emerging importance and relevance of shared decision making to clinical practice. *Medical Decision Making* 2010;5S–7S.
- [71] Stewart, M. Belle-Brown, J. Donner. A. The impact of patient-centred care on outcomes. *The Journal of Family Practice*, 2004; 49.9: 796–804.