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Supporting Patient Autonomy: The Importance of Clinician-patient Relationships

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Abstract

Personal autonomy is widely valued. Recognition of its vulnerability in health care contexts led to the inclusion of respect for autonomy as a key concern in biomedical ethics. The principle of respect for autonomy is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive. In this paper, we suggest that a strong focus on decision situations is problematic, especially when combined with a tendency to stress the importance of patients' independence in choosing. It distracts attention from other important aspects of and challenges to autonomy in health care. Relational understandings of autonomy attempt to explain both the positive and negative implications of social relationships for individuals' autonomy. They suggest that many health care practices can affect autonomy by virtue of their effects not only on patients' treatment preferences and choices, but also on their self-identities, self-evaluations and capabilities for autonomy. Relational understandings de-emphasise independence and facilitate well-nuanced distinctions between forms of clinical communication that support and that undermine patients' autonomy. These understandings support recognition of the value of good patient-professional relationships and can enrich the specification of the principle of respect for autonomy.

KEYWORDS: personal autonomy, professional-patient relations, clinical ethics, relationship-centred care

Personal autonomy is widely valued: most people think it is preferable to somehow be their own person and shape their own lives than to live under the control of others. Recognition of the particular vulnerability of patients' autonomy has underpinned the inclusion of respect for autonomy as a key concern in biomedical ethics.^{1–3}

In this paper, we highlight some limitations of prevailing ideas about the principle of respect for autonomy and argue that relational understandings of autonomy offer useful additional insights for clinical contexts. These understandings highlight the importance of social relationships for autonomy capability. We believe they could help clinicians to recognise how their interactions and relationships with patients can either enable or impair patients' autonomy.

RESPECT FOR AUTONOMY: PREVAILING IDEAS

Considerations of respect for autonomy in health care contexts tend to focus on situations in which decisions need to be made about health care interventions. A principle of respect for autonomy is also invoked in discussions about confidentiality, fidelity, privacy and truth-telling,¹ but is most strongly associated with the idea that patients should be allowed or enabled to make autonomous decisions about their health care.^{1,3–9} Beauchamp and Childress' influential definition identifies autonomous decisions as those made intentionally and with substantial understanding and freedom from controlling influences.¹

Various criticisms have been made about this construal of the principle of respect for autonomy.^{3–9} Some are more fairly levelled against simplified understandings of the principle that sometimes emerge in practice than against Beauchamp and Childress's nuanced discussion of it. They most strongly indict those understandings that put more emphasis on offering and allowing choice than on enabling informed decision-making—most notably the idea that respect for autonomy obliges clinicians to tell patients about health care options then stand back and abide by their choices. The concerns we outline below also apply most strongly to simplified understandings of respect for autonomy that emphasise the value of independence. But our concerns reflect Beauchamp and Childress' focus on autonomous decisions, and we do want to suggest there is scope to improve on their specification of the principle.

The idea that patients should be offered options and allowed to make voluntary choices about potentially life-changing health care interventions is important. It undoubtedly discourages some inappropriate paternalism and protects some patients from unwanted intervention, for example, by permitting individuals to decline surgery that they consider more burdensome than beneficial. The idea that patients should be enabled to make informed decisions also helpfully encourages attention to individuals' understandings of health care interventions, and supports the development and use of potentially autonomy-enhancing patient decision aids.¹⁰

We are concerned, however, that the strong association of respect for autonomy with autonomous decision-making has some neglected negative implications and that the focus on decisions distracts attention from other important autonomy-related issues—especially when there is an emphasis on the value of patients' independence in choosing.

A strong focus on decisions may impair clinical recognition of what limited autonomy some patients have. Beauchamp and Childress explicitly exclude people who are not 'competent' from the protection of the principle of respect for autonomy.¹ If clinicians are more inclined to offer and allow choice than to enable patients to make informed choices, the principle may also fail to protect those who are basically 'competent' but who struggle to choose between health care options because, for example, they lack confidence, are not sure which option they prefer, have conflicting priorities or anticipate blaming themselves if outcomes are poor. These patients may feel abandoned rather than autonomous if their clinicians refuse to do more than inform them about options and insist that they choose.¹¹

A strong focus on decisions can lead to neglect of other situations in which patients have problems with autonomy.^{3,5–7,9,12} Discussions about respect for autonomy rarely attend to the implementation of health care choices with significant self-management implications such as health-oriented lifestyle changes. So clinicians seeking to respect patients' autonomy might not be inclined to attend to the problems associated with weakness of will⁹ or limited 'executive function'¹², which impair people's efforts to enact their preferred behaviours to achieve their health-related goals (for example, to persist with eating, exercise and glucose-monitoring plans to avoid adverse complications of diabetes).

Finally, a strong focus on decisions may distract attention from health care practices that undermine people's autonomy by limiting their scope and confidence to act. In institutional care, for example, procedures are often standardised to ensure efficient completion of patient care tasks. Residents who are imposed on by these procedures may fear to challenge those on whose care they depend.⁵ Clinically imposed behavioural norms may also become oppressive. In antenatal settings, for example, women are sometimes required to shift their priorities, change their lifestyles and submit to judgemental monitoring by health professionals in the name of health promotion.⁷

More relational understandings of autonomy encourage attention to these issues.

RELATIONAL ACCOUNTS OF AUTONOMY

Relational accounts share with other accounts the basic understanding of personal autonomy as somehow being one's own person and shaping one's own life. What marks them out is that in seeking to assess and explain personal autonomy, they take seriously the ideas that individuals are always located within interpersonal relationships and broader social environments, and that these are pervasively influential.¹³ Relational accounts vary, but all emphasise the significance for autonomy of our interactions with other people and socio-cultural systems.¹³

Because relational understandings of autonomy accept the pervasiveness of social influences, they de-emphasise independence. They encourage us to consider our interdependence and to ask how and why different forms of social influence—past and present—might support or undermine a person's ability to live their life in their own way. The question of what is genuinely our own remains difficult, but relational accounts recognise that we may have multiple, dynamic self-identities because we belong to several social groups and have diverse roles within these.¹³ They stress that our individual capability for autonomy is socially and situationally shaped (see Box), and that cultural norms and social structures and practices affect the lives and identities we regard as valuable and possible for us.^{5,13} These ideas can help distinguish autonomy-supporting from autonomy-undermining social influences.

Factors contributing to autonomy capability:

Self-development skills

Relational accounts suggest various socially shaped skills are needed to exercise autonomy. Diana Meyers, for example, argued that in order to discover, define and direct ourselves, we need to be able to: recall and reflect on experiences; generate ideas about alternative courses of action; think through possible consequences; express and listen to reasons and concerns; gather resolve to act; and interpret one's own (emotional) and others' (variously communicated) responses to one's actions^{14,15}

Self-evaluations

Several relational accounts regard (justified) positive self-evaluations as essential for autonomy. For example, Carolyn McLeod drew attention to the requirement that people trust themselves to: work out what they want (especially if they have conflicting desires that reflect competing social norms); make good judgements (e.g., about which purveyors of information to trust); choose well; and act on their choices.¹⁶ Paul Benson stressed the importance of individuals' sense of themselves as competent and worthy to answer for their actions¹⁷

Scope for action within social context

Relational accounts vary in the extent to which they specify particular social conditions as prerequisites for the exercise of autonomy.¹³ All recognise, however, that interpersonal and broader social relations and social structures can exert both more and less direct influences on the options that people 'have'—both formally and more subjectively

IMPLICATIONS OF RELATIONAL ACCOUNTS FOR CLINICAL PRACTICE

Relational accounts encourage clinicians to consider patients' autonomy in situations beyond decision-making. They prompt us to consider how illness and clinical practice can affect patients' autonomy—positively or negatively—via their influence on autonomy capability as well as values and choices. It is widely recognised that illness can affect autonomy by challenging life plans, necessitating changes in relationships and disrupting self-identities.^{2,18} Relational thinking reminds

us that illness can also impair autonomy by restricting self-development skills and undermining self-evaluations, and that its effects are mediated by social norms and practices—particularly when symptoms or diagnostic labels are disabling or stigmatising.¹⁷

Significantly, relational accounts direct us to consider health care interactions and health services among the social processes and contexts that can exacerbate or alleviate the implications of illness for autonomy. They suggest that clinical interactions can support the autonomy of people with challenging symptoms, diagnoses or treatments by helping them to form, maintain or re-establish self-identities that they are comfortable with, and to deal with emotions and social stigma.⁵ Relational thinking would, for example, view efforts to help people with schizophrenia to develop life narratives that incorporate their condition as autonomy-supportive as well as potentially therapeutic.¹⁹

Relational thinking also suggests that dismissive and negatively judgemental comments can impair autonomy as well as signify disrespect. For example, a clinician who ignores or denies a patient's reports of symptoms or concerns, or who expresses annoyance that a patient is too heavy for standard hospital equipment, risks challenging that person's self-identity and undermining their self-evaluation (and so autonomy capability)—with negative implications for their autonomy within and perhaps beyond that particular health care encounter.

Relational accounts can enrich thinking about treatment decision-making. They encourage consideration of whether and how clinicians inform patients about a menu of options, but also about which options are (un)available and why.²⁰ They encourage questions about whether and how clinicians might help people assess external influences in relation to their own autonomy. Clinicians might, for example, draw attention to the values and interests behind advertisements for lifestyle drugs and beauty-enhancing surgical procedures, and encourage people to consider these against their own values.³ They might encourage patients to seek and use autonomy-supporting resources and networks such as relevant websites or patient groups.²¹

Because they highlight the socially shaped and situation-specific nature of autonomy capability, relational accounts can facilitate nuanced assessments of the forms of support clinicians might offer people usually deemed incompetent and people who struggle with particular decisions.

We previously suggested that recommendations about screening are more likely to be autonomy-supportive if accompanied by honest and meaningful explanations of their basis, facilitation of personal assessments of their appropriateness, opportunities for discussion and clear scope to reasonably decline recommended tests.²² Relational thinking suggests recommendations about treatment are more likely to be autonomy-supportive if made by clinicians who: seek to promote patients' autonomy and not just narrow health gain; listen to patients; explain how they have taken personal circumstances, concerns and preferences into account in their recommendations; enable patients to query and if necessary correct their understandings about them; and ensure patients feel they could choose against the recommendation without jeopardising their ongoing care.

The recognition that supportive relationships are sometimes more facilitative of enactments of autonomy than concern to allow independence is particularly significant for clinicians' efforts to help people manage their health conditions and risks. It suggests that clinicians can respect as well as promote patients' autonomy when they intervene to help them 'stick to' their behavioural goals—especially when patients recognise and own their difficulties and seek or welcome supportive intervention.²³

The difference between autonomy-supportive and autonomy-undermining communication might sometimes be subtle, and cannot be judged without understanding the significance of communication from the patient's perspective (and perhaps from the clinician's too). Because relational thinking often supports intervention as promoting autonomy, there is a danger that

misunderstandings and misappropriations of ideas derived from relational accounts could encourage the kinds of inappropriate paternalism that ethical norms of respect for autonomy are meant to protect against. Relational accounts will not generate simple action lists for clinicians that guarantee protection for patients' autonomy. Rather, by drawing attention to the significance of social relationships for individuals' autonomy capabilities as well as their values, they offer useful conceptual resources for thinking about the implications of health care for autonomy.

CONCLUDING REMARKS

Relational understandings of patient autonomy could underpin an enriched specification of the principle of respect for autonomy. They encourage recognition that concern about patients' autonomy is relevant in many health care contexts. They encourage clinicians to attend to the implications of health care interactions for patients' self-identities, life-plans and autonomy capabilities. They facilitate recognition of potentially oppressive aspects of health care regimens, and they support the development of respectful, bilateral relationships that enable patients to develop and exercise self-governance skills, both within and beyond health care encounters.

Relational accounts render all communication with patients potentially significant for their autonomy, and treat any interactions that belittle or undermine patients as potentially problematic. In this sense, they are demanding on clinicians. However, we think they will resonate positively with the values and practices of the countless clinicians who strive to act with integrity² and recognise the importance of relationships for good quality care.²⁴ Relational accounts of autonomy are congruent with patients' judgements that interpersonal relationships and engagement in activities other than choosing are important for their sense of involvement in their health care.²⁵ By broadening the focus beyond decision points and de-emphasising independence, they enhance scope for the exercise of professional expertise and caring alongside respect for autonomy.²⁶ The balance between allowing and enabling patients to make decisions (and, more generally, the balance between recognising and supporting exercises of autonomy) still needs careful consideration, but relational accounts should facilitate this. They could reinvigorate thinking about autonomy in health care, and they warrant serious consideration in discussions about clinical ethics.

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References

1. Beauchamp TL, Childress JF. Principles of biomedical ethics. 6. New York: Oxford University Press; 2009.

2. Pellegrino ED, Thomasma D. The virtues in medical practice. New York: Oxford University Press; 1993.
3. Sherwin S. A relational approach to autonomy in healthcare. In: Sherwin S, and the Feminist Health Care Ethics Research Network, editor. The politics of women's health: exploring agency and autonomy. Philadelphia: Temple University Press; 1998. pp. 19–47.
4. Schneider CE. The practice of autonomy. New York: Oxford University Press; 1998.
5. Dodds S. Choice and control in feminist bioethics. In: Mackenzie C, Stoljar N, editors. Relational autonomy: feminist perspectives on autonomy, agency and the social self. New York: Oxford University Press; 2000. pp. 213–35.
6. O'Neill O. Autonomy and trust in bioethics. Cambridge: Cambridge University Press; 2002.
7. Kukla R. Conscientious autonomy: displacing decisions in healthcare. *Hastings Center Report*. 2005;35(2):34–44. doi: 10.1353/hcr.2005.0025. [PubMed] [Cross Ref]
8. Gillet G. Autonomy and selfishness. *Lancet*. 2008;372:1214–5. doi: 10.1016/S0140-6736(08)61507-X. [PubMed] [Cross Ref]
9. Walker RL. Medical ethics needs a new view of autonomy. *J Med Phil*. 2009;33:594–608. doi: 10.1093/jmp/jhn033. [PubMed] [Cross Ref]
10. O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KD, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D. Decision aids for people facing health treatment or screening decisions (review). *Cochrane Database of Systematic Reviews*, 2009 issue 1.
11. Davies M, Elwyn G. Advocating mandatory patient 'autonomy' in healthcare: adverse reactions and side effects. *Health Care Analysis*. 2008;16:315–28. doi: 10.1007/s10728-007-0075-3. [PubMed] [Cross Ref]
12. Naik AD, Dyer CB, Kunik ME, McCullough LB. Patient autonomy for the management of chronic conditions: a two component re-conceptualization. *Am J Bioethics*. 2009;9(2):23–30. doi: 10.1080/15265160802654111. [PMC free article] [PubMed] [Cross Ref]
13. Mackenzie C, Stoljar N (Eds) *Relational autonomy: feminist perspectives on autonomy, agency and the social self*. New York: Oxford University Press, 2000.
14. Meyers DT. *Self, society and personal choice*. New York: Columbia University Press; 1989.
15. Meyers DT. De-centralizing autonomy: five faces of selfhood. In: Christman J, Anderson J, editors. *Autonomy and the challenges to liberalism: new essays*. Cambridge: Cambridge University Press; 2005. pp. 27–55.
16. McLeod C. *Self trust and reproductive autonomy*. Cambridge: MIT Press; 2002.
17. Benson P. 'Feeling crazy': self worth and the social character of responsibility. In: Mackenzie C, Stoljar N, editors. *Relational autonomy: feminist perspectives on autonomy, agency and the social self*. New York: Oxford University Press; 2000. pp. 72–93.
18. Carel H. *Illness: the cry of the flesh*. Stocksfield: Acumen; 2008.
19. Roe D, Davidson L. Self and narrative in schizophrenia: time to author a new story. In: Rapport F, Wainwright P, editors. *The self in health and illness*. Oxford: Routledge; 2006. pp. 83–95. [PubMed]

20. Wirtz V, Cribb A, Barber N. Patient-doctor decision-making about treatment within the consultation: a critical analysis of models. *Soc Sci Med*. 2006;62:116–24. doi: 10.1016/j.socscimed.2005.05.017. [PubMed] [Cross Ref]
21. Kukla R. How do patients know? *Hastings Center Report*. 2007;37(5):27–35. doi: 10.1353/hcr.2007.0074. [PubMed] [Cross Ref]
22. Entwistle VA, Carter SM, Trevena L, Flitcroft K, Irwig L, McCaffery K, Salkeld G. Communication about screening: a proposed new direction. *BMJ*. 2008;337(221):a1591. doi: 10.1136/bmj.a1591. [PubMed] [Cross Ref]
23. Dudzinski DM. Compounding vulnerability: pregnancy and schizophrenia. *Am J Bioethics*. 2006;6(2):W1–14. doi: 10.1080/15265160500506191. [PubMed] [Cross Ref]
24. Beach MC, and the Relationship Centred Care Research Network Relationship-centred care: a constructive reframing. *J Gen Intern Med*. 2006;21:S3–8. doi: 10.1111/j.1525-1497.2006.00302.x. [PMC free article] [PubMed] [Cross Ref]
25. Entwistle VA, Prior M, Skea ZC, Francis J. Involvement in decision-making: a qualitative investigation of its meaning for people with diabetes. *Soc Sci Med*. 2008;66:362–75. doi: 10.1016/j.socscimed.2007.09.001. [PubMed] [Cross Ref]
26. Mol A. *The logic of care: health and the problem of patient choice*. Abingdon: Routledge; 2008.