Autonomy and chronic illness: not two components but many.

Camilla Scanlan and Ian H Kerridge

Naik et al argue that ‘decisional autonomy’ is insufficient to account for non-adherence in the context of chronic illness and that what is required is a two-compartment re-conceptualisation of autonomy that includes both decisional autonomy and ‘executive autonomy’. While the authors correctly point out the concentration on the cognitive aspects of competence in the bioethics and medical literature, the model of autonomy that they propose is consistent with process or discursive models of consent, and with the work of Bergsma and Thomasma, Gillon, Beauchamp and Childress, all of whom describe the importance of action or enactment in medical decision-making. Indeed, while autonomy is usually defined in terms of self government, it can usefully be described as being a cluster of notions that together signify control of decision-making. Included in this cluster according to Bergsma and Thomasma is the ability to set life-plans, and the capacity to adapt to changing circumstances. To successfully carry out a decision three functions come into play (i) autonomy of thought (ii) autonomy of will and (iii) autonomy of action. It follows then that the patients in the study described by Naik et al have autonomy of thought (occurrent aspect), and of will (intentionality), evidenced by their participation in developing self management plans, but according to Gillon, are deficient in autonomy of action (disposition aspect). This agrees with Beauchamp and Childress’ principles underpinning autonomy as being liberty (independence from controlling influences) and agency (capacity for intentional action).

The primacy of autonomy in medical care has been extensively critiqued over the past two decades. Naik et al provide yet another reason to be sceptical of simplistic
formulations of autonomy and decision-making in medicine. At the same time, however, we believe that the authors continue to over-emphasise rationality, de-emphasise the social and relational basis of autonomy and agency, and provide an insufficiently complete model of capacity in chronic illness. As much can be seen by their description of ‘biopsychosocial correlates of autonomy’ which draws upon recent developments in neurobiology but says nothing about the social or relational basis of illness.

We report the results of on-going qualitative research with patients undergoing allogeneic haematopoietic stem cell transplant (‘bone marrow transplant’) for a range of haematological malignancies that suggest that the reasons for non-adherence may be much more complex than that provided by Naik and colleagues. The participants in our study were aged from mid twenties to sixty and none had any history of concomitant psychiatric disorders, or of diminished decisional capacity. All had received extensive education regarding transplantation. In each case, allogeneic stem cell transplant (allo-SCT) provided the only, or the greatest chance of long-term survival. One might assume, therefore, that these people would be highly motivated to adhere with the established management plan. In fact, a number of the participants in this study chose to ‘go against’ the established treatment regime; some chose not to take antibiotics, others refused to remain in isolation at the time when they were at high risk of infection due to lowered immunity, some continued to smoke during the transplant period when they were at high risk of serious respiratory infections, others took up their pre-transplant social and occupational ‘roles’ when this may have posed an infection risk, with one man carrying out physically demanding work including deconstructing an old shed and several cars soon after discharge from hospital and against medical advice. Given
that none had educational or cognitive barriers to executing their management plan, were their actions really a deficit in executive autonomy, or perhaps related to something else?

One of the problems with autonomy is that it fails to account for the moral significance of vulnerability in the setting of serious illness and dependency on healthcare and assumes that decisions are, and even should be rational. For in the context of chronic illness a person may do;

- the ‘right thing’ for the ‘right reason’
- the or ‘right thing’ for the ‘wrong reason’
- the ‘wrong thing’ for the ‘right reason’
- or the ‘wrong thing’ for the ‘wrong reason’,

and still be acting autonomously.

Patients choosing not to adhere with the agreed management plan were acting against their ‘medical best interests’ but were arguably acting in a way that restored control over their lives, and their illness.\(^4\) We would argue that if a patient elects to “take control” the only way he/she knows, or the only way that he/she can, by choosing to “do things their way”, as some patients in our study reported, then they may be acting autonomously, with capacity, and with rationality, insofar as their actions are consistent with their belief system and with the choices open to them.

In other words, assessments of an individual’s capacity to plan, sequence and carry out tasks only makes sense within the context of their life’s narrative and their illness experience and may be better understood through a broad construction of agency than through executive autonomy.

This is not, however, inconsistent with theories of autonomy, as there is frequently overlap between agency and autonomy, and autonomy may include reference to; (i)
sovereignty over him/herself (ii) ‘capacity’ to reflect on and identify his/her desires or preferences (iii) ‘agency’ i.e. is capable of rationally guiding one’s reasoned desires into actions and (iv) free will.

Benson defined the autonomous person as one who is able to …trust ones’ own powers and to have a disposition to use them, to be able to resist the fear of failure, ridicule or disapproval that threatens to drive one into reliance on the guidance of others.

While this seems clear, this idea is challenged by the context of serious illness, as patients have little choice but to rely upon medical expertise for their survival.

Dworkin and Frankfurt amongst others, believe that autonomy is a matter of the patient having capacity to reflectively control and identify with one’s basic (first order) desires through higher-level (second order) desires. This may be logical but it also assumes that anxiety, fear, or the desire to avoid death, all diminish functional autonomy – a rather narrow reading of the existential impact of serious illness.

Agency can be constructed purely in terms of rational choice. People may act in certain ways because it is the only thing that they can do, and patients may, for example, choose to undergo transplant not because their choice is a logical considered assessment of the burdens and benefits of treatment, but because, in the face of death, they believe they have no option. Likewise, non-adherence may, to others, seem completely irrational, but when one cannot do anything else to regain a sense of control over one’s life, then it becomes completely explicable. In this way, actions that seem entirely out of step with an agreed management plan may be entirely consistent with free will, according to Frankfurt’s construction of free will as the harmony between desires and volition of one’s values, or the subject of control by unconscious fear or desires.
Thus, while a patient’s non-adherence with management plans may be frustrating for their healthcare team (and sometimes for the patient’s family) we need to make a serious attempt to understand their situation and their perspective given that the choices that a person makes are only comprehensible within their individual, social, cultural and institutional context. Any useful conception of autonomy must therefore acknowledge the impact of illness on choice and behaviour and the influences, constraints and obligation that arise from the network of social relationships that envelope us.

Should we, as Naik et al, suggest, develop a means for testing the executive autonomy, resolve or intentionality of every patient prior to their commencing treatment for a chronic or serious illness? And what would we do if we identified a patient who appeared to have ‘weakness of will’ or who appeared more likely to have difficulty with adherence?

We would suggest that rather than developing more complex neurobiological or neuropsychiatric assessments, what is required is closer attention to a patient’s narrative and to the way in which acute or chronic illness may disrupt this narrative. This may both enable members of the healthcare team to understand why patients may act in the ways that they do and also assist them to construct a management plan more consistent with the patient’s particular goals, needs and capabilities. At times this may mean that health professionals will have to accept that non-adherence is a meaningful expression of a patient’s autonomy, and at times they may need to encourage patients to accept care and guidance from others.⁵ We would also suggest that while Naik et al are right to broaden the scope of thinking about autonomy, what is ultimately required is acknowledgement of the impact of
illness on independence and social relationships and the importance of trust, the provision of care and compassion.\textsuperscript{9,10}