

Medical complexity: treatable and untreatable traits – challenging health care to move onwards



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*"Clinicians must see and hear each patient in the fullness of his or her humanity in order to minimise fear, to locate hope (however limited), to explain symptoms and diagnoses in language that makes sense to the particular patient, to witness courage and endurance, and to accompany suffering. No biomedical evidence helps with any of this, so a rift runs through every consultation."*¹



In their paradigm shifting paper on treatable traits,² Alvar Agusti and colleagues describe the endotypes and phenotypes of patients with respiratory disease, mapping out variables such as genetic, radiological, pathophysiological and psychological profiles that affect the way an individual's condition may present, progress and respond to treatment. They make a compelling case for 'Precision Medicine', where each clinical decision is informed by the individual characteristics of the patients themselves, as well as the weight of research and clinical evidence, as applied to the thousands of patients in clinical trials, or as is extrapolated using meta-analyses.



It is tempting to see this approach as being able to solve the dilemma between 'population' and 'person' targeted health care, but as Iona Heath describes,³ it misses a whole other facet of the person engaging with their disease: their humanity.



In primary care, of course, we have an established and broader way of thinking about 'Personalised Care'. The three-legged stool of physical, psychological and social is fundamental, particularly when one leg is ignored and the stool is no longer stable.⁴ Although it is easy to recognise the physical (certainly from one organ that has pathology), intercalating different organ pathologies can be challenging – a situation we commonly see in people with both cardiac and respiratory problems. Well-being remains a complex mix of the physical, psychological and social domains of our lives.⁵

But do we really apply these principles in our everyday work? Can we broaden the concept of treatable traits beyond those of the human organism facing us in our clinic to consider the human being, their

likes and loves, habits and foibles, the multiple medical conditions they may have, and the unique way in which they choose to manage their health or illnesses. Who our patients are – their personality and character, the environment that surrounds and challenges them – will influence how they react to the changes in their fortunes brought about by illness. Furthermore, the symptoms and limitations of their illness not only affect them as individuals, but also their family, workmates and friends. This complex ecosystem has the potential to exaggerate or relieve these very symptoms and (perhaps) influence the course of their disease. Broadening this further, our own knowledge of the patient, their family and home environment, together with how we communicate and document this knowledge for colleagues, added to our own attitudes to issues such as religion, philosophy and life priorities result in a daunting holistic mix.

We are rightly encouraged to use techniques like cognitive behavioural therapy,⁶ motivational interviewing⁷ and other consultation models⁸ designed to support shared decision making⁹⁻¹¹ – however, in reality it is likely that the clinician will encounter not only treatable traits but also some untreatable traits lying in wait to trip them up.

Of course, these traits may be unrecognised by both the clinician and patient; at times they may be known to the patient but not the clinician; and even when recognised, their importance, degree of permanence and relevance may vary. Working together, there are opportunities for the clinician and patient to determine the impact of these untreatable traits.

Consider a teenage girl with asthma. A standard way of approaching this clinical problem would involve history taking, examination and application of evidence-based clinical guidelines as part of shared decision making.¹² In doing so, we may well practice our own version of 'Precision Medicine' by identifying the genetic features of her atopy, her own individual triggers and, for example, her responsiveness to leukotriene receptor antagonist therapy. As a part of this work, we have found at least some of her treatable traits. So far, so good, but what about all the other variables that contribute to her wellbeing?

How does the child feel about having asthma? How does this condition change her behaviour? The decisions she makes now such as concordance, smoking, exercise and diet may influence her prognosis decades into the future and contribute to the likelihood of her developing 'co' or 'multi'-morbidity. Her own and her parents' attitude towards (and understanding of) asthma also need to be explored, expanded and perhaps corrected.¹³ Also, the influences of peer group, social media and teen culture add further pressures to her unasked-for situation. Environmental issues such as pollution, smoke exposure and perhaps mould sensitivity (due to poor housing) directly influence the course of her condition but may not be possible to address.

Add to this the potential for lack of understanding or anxiety about asthma at school, in social clubs and extended family and what started as a two-dimensional clinical problem of which inhaled corticosteroid to choose now has a complex matrix of variables that need identifying and challenging and may, for the clinician at the coal face, feel like untreatable and overwhelming traits. The tendency for us to become didactic and "tell people what to do" easily flows from this situation, although the impact on health gains is less certain.¹⁴

We know that factors such as the patient's understanding of their condition, their relationship with their healthcare team and their confidence that their treatment can change their life for the better are key to successful self-management,¹⁵ but faced with time pressures and targets, we often find it impossible to deliver to this agenda. Recognising our own capacity as an adjunct (or barrier) to treatment may fundamentally change the way we practice and influence clinical outcomes for patients – another untreatable variable.

In an ageing community where those with multiple long-term conditions are becoming increasingly prevalent,¹⁶ this conundrum becomes even more complex. The older man with COPD, ischaemic heart disease, osteoarthritis and diverticulosis can be described, as we have just done, by his pathology. He can also be described by his socioeconomic status, his previous role in society (a retired miner), his religion, his choice of football team, or even just as Grandad. Each of his diseases impacts on each role, and each role on his lifestyle. Of course, his lifestyle will influence his current symptoms and future risk,¹⁷ completing a cycle of ever-decreasing diameter, limiting hope, ambition and ultimately survival. Add to this the challenges of his psychological status – he might be depressed, sad, or low. How does this affect the way in which we manage his care and are his symptoms normal or pathological?

It could be argued that we have been unconsciously encouraged to ignore this interaction by the application of evidence-based medicine through the Quality and Outcomes Framework. For laudable reasons we have set to work focusing on applying NICE to his COPD and his heart disease, as well as adhering to local guidelines on prescribing and referral pathways. We have withdrawn his non-steroidal anti-inflammatory drug following on from meta-analysis of their impact on estimated glomerular filtration rate and cardiovascular risk,¹⁸ and sent him off to the direct access colonoscopy clinic just in case he has more than diverticulosis.

When we consider his lot, we can see that he does indeed have treatable clinical traits – his tobacco dependence, breathlessness, osteoarthritis, angina and diverticular disease – some of which may have individual phenotypes of their own.

He may also have social problems including mobility, manual dexterity, housing, family challenges, money concerns, for which help may be required.

Psychologically, he may need referral for counselling or specialist help, but even if not, he is likely to have significant levels of anxiety, low mood and panic induced by pain or breathlessness as well as concerns linked to his ideas, concerns and expectations of his disease, its treatment and his life in general.

Getting 'under his skin', we may be able to identify traits that support empowerment or change, or traits that restrain this process to the point where it seems impossible to achieve. Some of these will be recognised by our patient and some (with the correct training) by ourselves, giving us an opportunity to facilitate change. This needs to be done as part of a collaborative process, involving patients in a shared management plan.

Improving these 'softer' outcomes may have a greater influence on his prognosis than the usual measurable ones used in traditional medical research.

These are the elements of his situation that are more likely to have the greatest impact on him and healthcare providers, thus putting the greatest strain on every aspect of society (as it meets and engages with him), and these lie far removed from the medical model of the past hundred years.

Faced with these apparently insurmountable problems, it is not surprising that our patient steps back from active involvement in his condition, divests responsibility onto others, becomes a passenger in his own journey and finds himself as another 'winter crisis' statistic. Of course this transfer of locus of control onto clinicians is exactly the model from which we have been trying for a generation to escape, and leaves the clinician feeling overwhelmed, tempted to see the patient as untreatable.

Transforming this doomsday scenario isn't easy but should be the foundation of our model for care moving forwards if we are to face the challenge of our national demography. Models such as the 'House of

Care¹⁹ offer solutions, but demand dedication and determination if they are going to succeed. They require a shift away from a model of data collection and treating the result to working collaboratively with our patients to get the best outcome for them. Most importantly, any such initiative that doesn't start with the patient, that isn't developed in collaboration with patients and doesn't acknowledge that true autonomy might mean ignoring the evidence runs the risk of replicating the mistakes of the past. Connected collaborative and truly integrated care means that it doesn't matter what door the patient uses to enter his 'house of care' for, as they say in 'Stockport Together', there is no wrong door.

As we begin to change our way of doing things, it is vital that we treat our patient as a person, a respected individual who has values, beliefs and concerns. It is better to support strengths and accept some weaknesses, agreeing how to move care forward for our patient – not for our databases.

For change we must. The inexorable conveyor belt of multiple comorbid people will not stop for us to catch breath. At the same time, the aspirations of guideline writers, commissioners, professional regulators and even patient/disease interest groups should not tempt us into a disease-orientated medical model.

Remembering what matters to our patients and what really makes a difference to their care, whilst at the same time acknowledging the treatable AND the untreatable is our task – a task for which we are uniquely qualified, if not always supported. A challenge for the future.

References

1. Heath I. How medicine has exploited rationality at the expense of humanity: an essay by Iona Heath. *BMJ* 2016;**355**:i5705. <https://doi.org/10.1136/bmj.i5705>
2. Agusti A, Bel E, Thomas M, *et al*. Treatable traits: toward precision medicine of chronic airway diseases. *Eur Respir J* 2016;**47**:410–19. <https://doi.org/10.1183/13993003.01359-2015>
3. Heath I. How medicine has exploited rationality at the expense of humanity: an essay by Iona Heath. *BMJ* 2016;**355**:i5705. <https://www.bmj.com/content/355/bmj.i5705.full>
4. Working Party of the Royal College of General Practitioners. The Triaxial Model of the Consultation. London: RCGP, 1972.
5. Stokes-Lampad H. Social prescribing and the current NHS landscape. 2017. <https://www.kingsfund.org.uk/audio-video/helen-stokes-lampad-social-prescribing>
6. Blane D, Williams C, Morrison J, Wilson A, Mercer S. Cognitive behavioural therapy: why primary care should have it all. *Br J Gen Pract* 2013;**63**:103–4. <https://doi.org/10.3399/bjgp13X663235>
7. Rubak S, Sandbæk A, Lauritzen T, Christensen B. Motivational interviewing: a systematic review and meta-analysis. *Br J Gen Pract* 2005;**55**:305–12.
8. Silverman JK, Draper J. Skills for Communicating with Patients. Oxford: Radcliffe Medical Press, 1988.
9. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997;**44**:681–92.
10. Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. *Br J Gen Pract* 1999;**49**:477–82.
11. Wilson SR, Strub P, Buist AS, *et al*. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *Am J Respir Crit Care Med* 2010;**181**:566–77. <https://doi.org/10.1164/rccm.200906-0907OC>
12. British Thoracic Society/Scottish Intercollegiate Guideline Network. British Guideline on the Management of Asthma. 2016. <http://www.sign.ac.uk/assets/sign153.pdf> (accessed Dec 2017)
13. Matthys J, Elwyn G, Van Nuland M, *et al*. 2009. Patients' ideas, concerns, and expectations (ICE) in general practice: impact on prescribing. *Br J Gen Pract* 2009;**59**:29–36. <https://doi.org/10.3399/bjgp09X394833>
14. Holmes S, Scullion J. Improving Asthma Care: Effective communication – effective care (an educational resource). Liverpool: PCRS/REUK, 2013.
15. Taylor SJC, Pinnock H. Supported self-management for respiratory conditions in primary care. *PCRU* 2017;**4**(3):11–15.
16. Barnett K, Mercer SW, Norbury M, *et al*. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012;**380**:37–43. [https://doi.org/10.1016/S0140-6736\(12\)60240-2](https://doi.org/10.1016/S0140-6736(12)60240-2)
17. Bateman ED, Reddel HK, Eriksson G, *et al*. Overall asthma control: the relationship between current control and future risk. *J Allergy Clin Immunol* 2010;**125**:600–8, 608.e1–608.e6. <https://doi.org/10.1016/j.jaci.2009.11.033>
18. Zhang X, Donnan PT, Bell S, Guthrie B. Non-steroidal anti-inflammatory drug induced acute kidney injury in the community dwelling general population and people with chronic kidney disease: systematic review and meta-analysis. *BMC Nephrol* 2017;**18**:256. <https://doi.org/10.1186/s12882-017-0673-8>
19. NHS England. House of Care – a framework for long term condition care. <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care>.