

Debate & Analysis

In this uncertain world, patient-centred care must not mean patient-led care

NAVIGATING THE DIAGNOSIS

Picture the scene: you are climbing down a mountain and the fog descends. You can no longer see further than 5 metres. The two-dimensional map you are following does not capture the three-dimensional landscape you are navigating; you cannot get your bearings, and you do not know what is coming. Now imagine that you are with a guide who has walked the path you are on thousands of times before. What would you want them to do?

The similarities between helping an individual to navigate a treacherous mountain and the process of making a diagnosis and treatment plan in primary care make this a pertinent analogy. The primary care physician navigates undifferentiated diagnostic situations, simultaneously processing the biological, psychological, and social aspects of the presentation.¹ This process of decision making in the face of uncertainty requires learnt intuition: utilising the technical, personal, and conceptual skills of the GP. These skills arise from prolonged practice, exposure, and feedback.² Just as the mountain guide draws on their honed intuition to provide a path to safety, so too does the GP.

However, this professional intuition is under attack. An article in the *Telegraph* proposed that we should do away with GPs and that the public should provide their own primary care with 'apps, robots, online self-diagnosis and over-the-counter medicines'.³ A popular view is that this is the natural extension of patient-centred care, facilitating patients to make informed, autonomous decisions. But if patients are being asked to sort and prioritise their own symptoms, and analyse and choose options available to them, this is not so much patient-centred as patient-led care.

ADVERSE CONSEQUENCES OF PATIENT-LED CARE

Although there are some conditions and minor illnesses for which this patient-led approach will be effective, unfortunately there are also many situations where this approach may be ineffective and/or dangerous. The clinical process is shrouded in uncertainty. GPs apply their skill and experience to rule out or investigate the worrying and sinister causes, and frequently utilise watchful waiting and best-fit treatments as diagnostic tools. They

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take responsibility for the uncertainty (a therapeutic action in itself?) until a way is found off the mountain.

If patient-led care is allowed to develop along the proposed trajectory, the uncertainty remains with the patient. Several possible adverse consequences can be foreseen: to the individual patient; to the distribution of health care; and to the healthcare system as a whole.

Harm via abrogation of responsibility

This will be seen in the cohort of individuals who are risk averse and who will be susceptible to increased investigations and treatments. The inherent uncertainty of what might be causing a symptom will persist in an algorithm-generated differential diagnosis.² A tech company will be less willing to take emotional or litigious responsibility for a missed diagnosis and so the list — perhaps with relative risks — will be passed back to the patient. A natural response is to resolve this uncertainty, and the potential accompanying anxiety, by seeking help through self-referral to a specialist. The patient would then need to find the right specialist — a challenge in itself.⁴

This is without taking into account that 15–39% of GP consultations are for symptoms that are medically unexplained.⁵ It takes a skilled GP to contain and manage medically unexplained symptoms in primary care: by processing the biological, psychological, and social aspects of the presentation, often over time. Furthermore, many patients with mental illness present with biological or somatic symptoms. In these situations, the GP is key to establishing a diagnosis and avoiding counterproductive

investigations and overmedicalisation. It is easy to see how the proposed pattern of self-referral could lead to over-investigation, overmedicalisation, and iatrogenic harm.

Neglect

Other consequences will arise in the cohort of individuals who for any number of reasons take less ownership over their health. It has been shown that certain cohorts of patients do not wish to be involved in the decision-making process.⁶ This may be due to age,⁷ lower health literacy, socioeconomic status, or a more risk-tolerating personality type. In these patients, one can see how a requirement to self-report and self-process uncertainty could lead to a dismissal of symptoms or a reticence to act, and consequential harm being done through inaction.

Widening of the health gap

These two first potential harms — of some patients being over-investigated while others become more disengaged with their own health care — could lead to greater inequalities for those who are less financially or educationally privileged. Variations in patient preferences for autonomy have been demonstrated among different ages and cultures.⁸ Societal variations between socioeconomic groups, ages, and cultures could lead to a widening of the health gap. Other consequences will be seen across all patient populations.

Missed diagnoses

An algorithm may miss important diagnoses. Pattern recognition is only possible when the correct information has been obtained and an algorithm only has

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the information that is given to it by the patient, not excavated by a physician picking up on ‘cues’. The symptoms that a patient may dismiss as unimportant may be the key to the diagnosis.⁹

Impact on mental health

There may be psychological harm (or the removal of psychological benefit) in giving responsibility to the patient for decision making and weighing uncertainty. A 2006 observational and interview study suggested that patients desire to be involved in decision making, as opposed to taking responsibility for it.¹⁰ In fact, they felt that having sole responsibility for their decision making was detrimental. When doctors become patients, this distinction is highlighted: Dr Ingelfinger, a renowned gastroenterologist who received a diagnosis of adenocarcinoma of his gastroesophageal junction, has written about his own experiences. He found himself paralysed by uncertainty, confusion, and emotional distress. Despite his extensive knowledge of the field, he realised that he needed someone to tell him which path to take — as his friend said, ‘*what you need is a doctor*’.¹¹ The impact of handing over responsibility for diagnostic uncertainty to the patient is unknown, and should be investigated.

Impact on infrastructure and research

General practice currently absorbs 300 million patient contacts a year while A&E sees 23 million patients.¹² Secondary care could not survive if even 10% of these patient contacts were relocated. As the NHS Five Year Forward View states: ‘*if general practice fails, the NHS fails*’. Perhaps of equal concern is the threat to medical innovation that artificial intelligence poses. Many medical advances have been made by clinicians who through their clinical experiences look to explore old problems from new angles. By relocating clinical decision making to machines, the outcomes may be more efficiently delivered. However,

will this increased distance from the clinical process limit research and progress?¹³

ENHANCING THE GP ROLE

How will we respond to this threat to both our profession and to our patients? The professional intuition of a GP must be preserved and enhanced. Work is needed to understand the nature of the uncertainty present in primary care, how it is managed and communicated,¹⁴ and what patients think about the physician’s (changing) role in this process. These priorities must be reflected in the training of the future generations of GPs and in the research agenda. We must evolve and progress, using the full scope of advantages that technological innovation brings in order to enhance the role of the doctor rather than replace it; technologies must be evaluated in a robust manner before they are adopted due to perceived cost-savings or convenience.

For now, for our patients’ sake, we must ensure that we continue to provide doctor-led, patient-centred care.

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