



Surveillance imaging in primary sclerosing cholangitis (PSC): evidence, patient preference and physician autonomy

Philip A. Berry, Sreelakshmi Kotha

Department of Gastroenterology, Guy's and St Thomas' Hospital, London, UK

Correspondence to: Philip A. Berry. Department of Gastroenterology, St Thomas' Hospital, Westminster Bridge Road, London SE1 7JD, UK.

Email: philaberry@hotmail.com.

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Rabiee and Silveira's recent article on primary sclerosing cholangitis (PSC) comments on surveillance for cholangiocarcinoma, and highlights an area of ongoing controversy (1). They write, '*Though guidelines do not universally recommend surveillance for CCA a retrospective study including 79 patients with PSC who developed hepatobiliary cancer revealed that patients who underwent surveillance had a significantly improved 5-year survival compared to the no-surveillance group (68% vs. 20%).*' Current guidelines in the United Kingdom advise a conservative approach, with magnetic resonance imaging (MRI) recommended only if clinical condition changes (2). Clinicians have argued against this, citing studies suggestive of clinical benefits from routine surveillance and contradictory advice from international societies (3).

As in other areas of medicine, decisions around surveillance need to take into account overall clinical and economic factors. If hundreds of thousands of patients with a certain condition require surveillance annually, the threshold at which this should commence will have a huge impact on resources. Correspondingly, a physician who elects to scan their patients annually because they interpret the evidence differently could be criticised. Despite this, there is enough latitude in most health systems for doctors and patients to settle on an approach that is comfortable for them. Given that PSC is rare, but carries a risk of cholangiocarcinoma in 10–15% of patients, the economic argument may be less relevant, justifying a more individualised approach.

During the COVID-19 pandemic the 'precautionary principle' has been used to justify the wearing of masks

in the absence of strong evidence (4). The public are now more aware of the evidence-based practice and guidance, and of the difficulties that waiting for large, well-designed trials presents. Are present dangers and associated unknowns sufficient to overthrow evidence-based principles? What if we deny a generation of patients' surveillance now, but learn in ten years' time that lives could have been saved? And where do patients' preferences come into this debate?

Uncertainty about prognosis is associated with morbidity in PSC (5). Patients have expressed strong desires to the authors of this letter to have regular scans, in order to know how their disease is progressing and perhaps have some sense of control. Conversely, we know that surveillance can be associated with physical and psychological harms. Presently, hepatologists and patients are caught in a conflicted, uncertain zone; together they must find a path between guidance, patient preference and physician autonomy. While research continues into the effectiveness of surveillance in PSC, patient preferences and the effect on well-being should be studied in parallel.

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