

Making a Difference – an essay inspired by a patient for whom a result from a pathology department made a big difference

By Keir Edwards

Word count: 992

One morning while working in the haematology department, our ward round filed into the room of Mr B, a young man we had been asked to see after some worrying findings on a blood film. “As you know, your blood tests showed some abnormal cells under the microscope” the consultant began. “Unfortunately, the bone marrow samples confirmed our suspicions. The high number of blasts suggests you're suffering from a condition called Acute Myeloid Leukaemia, a type of blood cancer.” The conversation continued, covering chemotherapy, immunophenotyping, cytogenetic markers and HLA typing, while the patient sat in stunned silence. It was a scene I had witnessed before, a single result thrusting a patient into a new and unfamiliar world; an uncharted landscape of inscrutable acronyms and daunting treatment regimes, of ara-C and FLAG-ida, FLT3 and CD33.

As a junior doctor, I have often felt dispirited in these situations. My initial reaction would be to offer explanation and guidance though such a diagnosis, but all too often I would come up against the limits of my own knowledge. In a medical landscape of ever increasing complexity and sub-specialisation, how do we help our patients understand and process results with life changing implications?

On the one hand, there is an ever increasing drive towards patient autonomy. Information is easier to access than ever before, and we strive to educate patients, allowing them to make informed decisions. On the other, accelerating advances in medical diagnostics and treatment threaten to outpace these efforts. Nowhere is this more true than in the field of pathology, with genetic and molecular diagnostics allowing us to characterise patients' diseases in ever greater detail. We have a responsibility to help our patients understand the implications of this, and haematologists are an important part of this process. However, what role is there for typically “behind the scenes” specialities, such as histopathology? Histopathologists deal with life changing results every day. Sadly, their knowledge and expertise is often overlooked in its potential to help patients understand these results. There are two ways this valuable asset could be brought to the fore.

Firstly, through public engagement and outreach. Despite its importance, pathology remains a relatively unknown speciality. Patients – and some doctors - often know their samples “go to the lab” and results come back, but are unaware of the work that goes on to make this happen. It is important to appreciate the value of social media in addressing this. For example, as part of the RCPATH National Pathology Week 2018, their “what is a pathologist” animation was viewed 48,000 times on numerous platforms.¹

Secondly, direct patient contact should not be underestimated. More informally, involvement in patient support groups can yield benefits for both parties.^{2,3} Pathologist Dr Jerad Gardner

writes movingly about his experiences with a Facebook support group for angiosarcoma sufferers.³ For patients, the knowledge and support he was able to share had a hugely positive impact, while for Gardner, the experience offered a richer understanding of the disease, and of the fortitude and courage of those suffering from it. More recently, Haller et al. surveyed 542 patients and family members from rare tumour support groups on Facebook – including those with and without pathologist support⁴. Of those with pathologist support 90% felt this helped them better understand their disease and 77% that it reduced disease related anxiety.

In a more formal manner, consultations between histopathologists and patients may also be beneficial. Histopathologists are in the unique position of delivering life changing results without being able to explain them face-to-face, relying on written reports interpreted and relayed by a clinician. With such a disconnect, nuances of the result and a broader explanation of its significance risk being lost in translation. Booth et al. demonstrated the value of such consultations⁵. Over one year, patients with a new diagnosis of cancer were invited for an optional consultation with a pathologist. The pathologist guided the patient through their case on a multi-headed microscope, comparing it to normal tissue and answering questions as they went. Although uptake of the consultation was low, (31 of 1615 newly diagnosed patients), the survey response post-consultation was encouraging. 89% strongly recommended the experience to another patient, while 78% felt more empowered in managing their disease. One patient stated she would have taken her tamoxifen as prescribed if she had seen the oestrogen receptor positivity of her tumour cells under the microscope earlier.

Although this is an exciting prospect, there are practical limitations to introducing a similar programme in the NHS. The low take-up rate suggests this would be attractive to a minority of patients who are motivated to learn more about their disease. Even so, in an already strained health system, finding the resources to cater for even a small cohort would be challenging. Furthermore, limits on the nature of the consultation would be needed, avoiding questions of treatment and prognosis that may conflict with information from their clinician. Although it has been suggested that consultations may leave histopathologists open to litigation, Manek et al.⁶ illustrate how explanation of the diagnostic process and its inherent uncertainty can in fact leave patients more understanding of the challenges faced by pathologists.

Several weeks later, I saw Mr B again, admitted with a Hickmann line infection. He talked fluently about his latest chemotherapy regime, the minutiae of preparation for allograft and his latest neutrophil and platelet counts. He had come face-to-face with a truly life changing result and gradually begun to understand the complicated and daunting world into which it thrust him. Guiding patients through this process in the complex and changing landscape of modern pathology is a major challenge, and one can be met by histopathologists as well as those in traditionally patient facing specialities. The stereotype of the histopathologist as shunning patient contact is wearing thin. It is time to recognise the value face-to-face engagement, and embrace the unique perspective histopathologists could offer patients on what could be the most important result of their life.

References:

- 1) The Royal College of Pathologists "National Pathology Week 2018"
<https://www.rcpath.org/discover-pathology/events-landing-page/national-pathology-week.html> (Accessed 25/08/2019)
- 2) Gardner JM. (2017) "How Angiosarcoma and Facebook Changed My Life." *Arch Pathol Lab Med* 2017 Feb;141(2):188.
- 3) "A cancer patient and pathologist — brought together by Twitter — strike up an unlikely connection" (2016) <https://www.statnews.com/2016/10/17/lung-cancer-patient-pathologist/> (Accessed 25/08/2019)
- 4) Haller J et al. (2018) "Impact of Pathologist Involvement in Sarcoma and Rare Tumor Patient Support Groups on Facebook: A Survey of 542 Patients and Family Members." *Arch Pathol Lab Med*. 2018 Sep;142(9):1113-1119.
- 5) Booth AL et al. (2019) "'Please Help Me See the Dragon I Am Slaying': Implementation of a Novel Patient-Pathologist Consultation Program and Survey of Patient Experience." *Arch Pathol Lab Med*. 2019 Jul;143(7):852-858.