Transforming the delivery of health and social care: the case for fundamental change

The majority of my workload at the minute as a GP trainee in a busy maternity unit is the diametric opposite to the care we give people at the end of their lives. Babies are planned for meticulously, their birth plans are discussed with their parents, and the mother is meticulously screened to ensure that the pregnancy has every chance of succeeding. People decide how and when they are to attend hospital, in what circumstances they will deliver, the type of pain relief, and often the position in which they choose to deliver. Babies are given the best possible welcome to a cold, frenetic start in life.

Compare this to 70 years later, on average, and you will find a different picture. People languish in symptoms of their progressive disease states, remember that diabetes mellitus, chronic heart failure, and dementia are all incurable diseases. On reflection most current medicine is palliative; there are few curable disease states within medicine. Death is a certainty, no one has escaped and no one will escape. Some of us will develop end-stage chronic lung disease, end-stage heart failure, or dementia and we should plan for how the end of our lives is spent.

The reality is, demonstrated by the King's Fund report,¹ that we are getting older and that the years added are not necessarily healthy years. We do not realise that as time passes we are less likely to tolerate an acute deterioration in our already faltering chronic disease. Hospitals and further medicines can buy time; further unhealthy months or years to our lives, but as patients and doctors we should be realising that there are finite limits to what can be done.

Let us recognise that death comes to us all, some of us can plan for the end and let us embrace the end of our lives as we celebrate birth. Plan for how or where you would like to be cared for, what symptoms of dying concern you the most, what spiritual needs you should have honoured at the end of your life, and importantly how you should be remembered. Death is inevitable, but empower yourself, make a plan for how you see the end of your life, and allow friends and family to support you

as you leave this world, just as the friends and family of your parents supported you into it.

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HIV testing: the danger of keeping secrets

During the 1980s and early 1990s, the advocacy group ACT UP (AIDS Coalition To Unleash Power) had a slogan: 'ignorance = fear, silence = death'.¹ McElveen's comment on information silence about HIV infection between primary and secondary care reminds us that the message is still relevant today. However, the solution is more complicated than making communication of a patient's HIV status to their GP automatic.

HIV infection hidden from primary health care is already a sizeable challenge: 20–49% of people living with HIV choose not to disclose their status to GPs;^{2–8} a legacy of the historical and deep-seated stigma surrounding this condition. Without action, this challenge will grow with HIV prevalence.

Non-disclosure becomes a more significant problem in the context of economic constraint. Previously, the HIV specialist could manage a variety of ailments for the HIV patient, but prescribing of non-antiretroviral therapy (ART) is increasingly being devolved to primary care. ART interacts with many commonly prescribed medications; for example, simvastatin, omeprazole, midazolam. Drug interactions are exceedingly complex and need considered management with expert advice. An invaluable and comprehensive resource is the Liverpool drug interactions website (www.hiv-druginteractions.org). Benn *et al* found devolution of statin prescribing from HIV specialists to GPs led to life-threatening drug reactions, where GPs were fully informed of HIV status.⁹

Clearly, if the primary care prescriber is unaware of the patient's HIV status and ART use, they cannot consider the risk of drug interactions.

Non-disclosure originates in discrimination of people living with HIV: fear of discrimination drives the insatiable need for confidentiality. McElveen is quite correct in that we are only strengthening this attitude by allowing it to overshadow information sharing for comprehensive care. Yet discrimination is an unfortunate, and unacceptable reality. Some fear communication between HIV specialists and GPs will cause information to leak out to non-clinical staff.^{2,8} From experience, this can happen and lead to enacted stigma. Such experiences can erode the patient-doctor relationship, which is of utmost importance in HIV. A poor relationship may lead to patient dissatisfaction, related non-adherence to medication, resistant, and progressive disease as well as transmission of hard-to-treat virus.

To draw an oft-presented analogy, confidentiality is the plaster to the infected wound of stigma and discrimination. Policies of non-discrimination are more effective than policies of confidentiality in facilitating patients to disclose their HIV status to GPs.² GPs are positioned to address patient concerns: participatory action techniques using group discussion would allow local problems to be unearthed, understood, and addressed through education and personal experience. The HIV specialist is positioned to perform surveillance of non-disclosure, and encourage disclosure. McElveen argues that we change practice to protect the patient. We agree, but the balance between patient safety and confidentiality is underpinned by discrimination. We must act to make our spaces safe: there should be no legitimate fear of discrimination for people living with HIV within health services.

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