An extremely interesting time to die

PERSONAL VIEW Ann McPherson

It is now almost 14 years since I wrote my last personal view for the *BMJ* (1995;310:1339). At that time it was about being given a diagnosis of breast cancer, the treatment and prognosis of which have now improved immeasurably, such that currently breast cancer is more a “chronic” condition than a death sentence, with a five year survival rate of up to 90%. But what about the pancreatic cancer I now have, with a five year survival rate of 4% or worse? Two years after a Whipple procedure I was last week found to have a recurrence of my primary cancer, with secondaries in my lung. These are the bare facts. But in spite of their grim significance for me, this really is an extremely interesting time to die, given the present debates over resources, the rulings of the National Institute for Health and Clinical Excellence, developments in palliative care, arguments over assisted death, and the possibility of now being able to see dying as something to be respected and celebrated as a finally fulfilling experience rather than a technological failure.

There are those who think that, with the excellent palliative care now available, no one would want to choose the option of assisted dying. And yet more than 800 people in the United Kingdom are known to have signed up to Dignitas because they hope to ensure that they will be able to die with dignity. This confirms my personal experience during my 40 years as a general practitioner that some people who are facing a terminal illness still want, in spite of adequate pain relief, to die more quickly and with more certainty about how, when, and where they will die. I remember feeling that I had failed a patient who was also a health professional and who was terminally ill with cancer: she had stockpiled various drugs to give her control over her time of death. Unfortunately she had a sudden obstruction of her bowel and could not take the pills when she wanted to. She was therefore furious when she ended up in an excellent hospice where she survived for another 10 days—just what she did not want.

In fact, supporting and respecting the wishes of terminally ill people in the timing of their death has recently become much more difficult. I was threatened with being reported by a nurse who thought that I had given too much analgesia to a patient dying of cancer who had become paralysed and who, in spite of good pain relief, still wanted to die. Undoubtedly, in these post-Shipman days, fear remains among my fellow medical professionals about overstepping the guidelines when helping patients who have a terminal illness. But this surely must be tempered by the need to listen to the patient’s own wishes. The choice should be there. Part of the problem is that those deciding on the legal and political issues concerning assisted dying are not those facing immediate death themselves but those running hospices (who may have a vested interest against assisted death), bishops in the House of Lords (who have a particular view on life and death), and others in positions of “authority.”

For me, at the moment, there is the need to achieve a balance between living as normal a life as possible but, at the same time, making the very most of my last living days as I wait to die. Of course, this includes seeing as much as I can of my children and grandchildren and at the same time leaving the DIPEx health experiences group, which I cofounded and help to run, in good order and in good hands, along with the www.healthtalkonline.org website. I do, however, have to admit that I get considerable relief from the knowledge that

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I no longer have to worry about the next research assessment exercise, as I simply will not be around, and that recently when I was caught speeding (the first ever time in my life) I opted to pay the fine rather than attending the offered “retraining” course.

My major regrets are that I will know less about the future, particularly concerning my children and grandchildren, than I want to, and that so many unanswered questions still remain that pop into my head during my long sleepless hours at night. For example, why does taste change during illness? Why does pancreatic cancer have a much worse outcome than other cancers? Why can’t people have a rational discussion about assisted dying? Why can’t assisted dying be available in Britain for those who want it as a choice? And why oh why is the BMA opposed to physician assisted suicide and euthanasia?

Surely now we are a culture that has developed enough humanity to provide the choice and still protect the vulnerable.

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The menopause became a lucrative niche ripe for exploitation and the role of drug companies merits further exposure

The idea that women are biologically inferior to men has a depressingly long trajectory in Western civilisation. Prejudices concerning the modern menopause can be traced back to Aristotle and Galen. The belief that menstrual blood was a foul excretion was regularly repeated in medieval times. “Whosoever were to take a hair from the pubis of a woman and mix it with menses and then put it in a dung heap would at the end of the year find wicked, venomous beasts,” said one French observer. Louise Foxcroft’s entertaining book traces a history of the climacteric from classical times to the present day—but makes grim reading for (male) doctors.

Most of the humane exceptions in an otherwise gruesome cast list are, of course, women—though not quite all. John Fothergill’s sensible essay Of the Management Proper at the Cessation of the Menses (1774) stated: “Nature is sufficient to provide for her own security on this occasion.” His advice was being echoed nearly two centuries later by such as Marie Stopes: “Do not anticipate any trouble at all at this time.”

Otherwise, as medical science began to colonise the bodies of women, the menopause was transformed from a natural phenomenon into a disease and a form of purgatory for older women. Eighteenth century physicians such as Henry Manning threatened menopausal women with a long list of symptoms, including headaches, haemorrhages, “hysterick” motions, loin pains, fits, and redness of the face. Pierre-Aimee Lair (1769-1853) even documented cases of spontaneous combustion involving post-menopausal women. Their only hope of redemption was to be transformed—surgically or chemically—into some simulacrum of youth.

The 19th century drive for medical professionalisation formalised new theories, bestowing on prevailing medical assumptions the status of “scientific truth.” The struggle for specialist status involved the designation and categorisation of diseases to legitimise the positions claimed. Gynaecology was firmly linked to various nervous disorders such as hysteria. (As a student I was taught about something called “involutional depression” suffered by women after the menopause.) The instability of female minds and bodies became a medical fact, and new interventions were developed to bring them under control.

Edward Tilt (1815-1893) attempted to establish a scientific basis for explaining the menopause. He studied 500 women “at the change of life” and listed 120 infirmities, subdivided into seven “distinct modes of suffering.” His list of remedies included bleeding, purgatives, sedatives, opiates (sometimes applied rectally), belladonna, lupulin, and chloral hydrate. Sexual arousal at the menopause was an “anomalous if not morbid impulse, depending on either neuralgic or inflammatory affections of the genital organs.” Because of this Tilt thought it “unreasonable to marry during this period” unless the “sanction of a medical advisor” had been obtained.

By the late 19th century the menopause was a veritable midlife “crisis.” Surgeons took control of the uterus and ovaries, whipping them out to induce an artificial menopause that would cure the patient of almost any symptom, especially mental states such as depression. Nymphomania was a favourite, for disapproval of sexual activity for pleasure among older women was widespread. Many women died needlessly before sterilisation and anaesthesia were perfected, and hysterectomy is still routinely performed for sometimes dubious reasons.

In the 20th century endocrinology provided a wonderful new magic bullet. The American gynaecologist Robert Wilson considered the climacteric a tragedy “borne bravely by women, but . . . hardly endurable” as it turned them into “castrates.” Only hormone replacement therapy (HRT) could make them acceptable again to their horrified husbands. By the end of the century HRT had received its own health warning.

Feminism and Foucault are blended here to erudite effect. The book is written with fluency and verve, but Foxcroft’s wit masks real anger—and with good reason. At best the medical men portrayed here, albeit selectively, are blinkered and patronising. At worst they are cruelly misogynistic. However, the social construction of the menopause and negative attitudes to older women are not the work of devious doctors alone. The treatments described here say more about the unpredictable development of science than medical conspiracy. Such development combined with other forces to generate insecurity about ageing and loss of fertility in our society.

Medicine has always been “politics and economics as well as knowledge and craft.” The menopause became a lucrative niche ripe for exploitation, and the role of drug companies merits further exposure. Nowadays most doctors spend more time trying to dissuade women from HRT than inflicting it on the unwilling.

In her final chapter Foxcroft fights back against the “medicalisation of life.” The menopause may be problematic, but it does not necessarily require drug treatment or surgery. The cultural meanings of the menopause may be unclear, but that is not the fault of women’s biology. Unless a woman is struggling badly with its consequences, and her quality of life is really diminished, the future of the menopause rests in self management and not in doctor driven “cures.”

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The stage of life at which I desired more possessions is, thank goodness, now long past. On the whole I am content to be rather than to have—with one notable exception.

Antiquarian booksellers now send me their catalogues through the post, and last week I received two such. One was a joint production of two Parisian dealers and was itself a book of rare beauty. As soon as I opened it I realised that I had wasted my life completely and should have spent it in the singleminded pursuit of money so that I could have bought these wonderful medical books of the 15th and 16th centuries.

For example, there was Magnus Hundt’s Anthropologium de Hominis Dignitate, Natura et Proprietatibus, published in “Liptzick” (Leipzig) in 1501, with wonderful woodcuts of the pre-Vesalian notions of human anatomy—for £70000 (£80000; $115000); or the first printed book of anatomy, Mundinus’s Anathemia, 5th edition 1493 for only £30000. If anyone, having bought Hundt or Mundinus, doubted that the Renaissance really did bring a revolution in human knowledge, they could compare those books with Andreas Vesalius’s De Humani Corporis Fabrica of 1543, against the description of which were delicately affixed the letters P.s.d. (Prix sur demande, or price on application). If you have to ask, you can’t afford it.

Reluctantly acknowledging that I was out of my financial depth, I turned to the other catalogue, where I was much tempted by a cyclostyled piece of tourist information. It said: “The people of Malawi so love their Kamuzu Banda. He was the doctor who practised for several years in north London before becoming the first president of Malawi.

When he was a student in America, Dr Banda spent all his money on rare books, often going without food to buy such items as a first edition of Burton’s Anatomy of Melancholy (which now you couldn’t buy even if you starved yourself to death). He accumulated a rare and valuable library.

My first contact with Dr Banda was at several removes. Arriving at my hotel on my first night in the country, I was handed a cyclostyled piece of tourist information. It said: “The people of Malawi so love their Kamuzu, His Excellency the Life President, that if any foreigner has come to overthrow him, they will cut him up and throw him to the crocodiles.”

Theodore Dalrymple is a writer and retired doctor and was formerly known as His Excellency Banda. He was the doctor who practised in “influential books” for “up to 10000 infant deaths in the UK and at least 50000” in the rest of the developed world. Its authors noted that the advice remained unchanged until well after persuasive evidence of harm was available. Under fire from feminists, the 1976 edition of the book stopped advising exclusively to the baby as “he.”

Perhaps reflecting his training in psychoanalysis as well as paediatrics, Spock advocated parental flexibility and child care that is based on “what good mothers and fathers instinctively feel like doing.” Thus began Dr Spock’s unrivalled career as a childcare expert, one whose influence derived in part from his insistence that parents were the real experts. The book’s popularity led to scores of translations, foreign editions, and sales numbers that are commonly compared to those of the Bible. A 1974 contributor to the BMJ suggested that children of that era were “not pock-marked but Spock-marked.” The phrase, which dates to 1967, according to the Online Dictionary of Etymology describes those “affected by upbringing in accordance with the principles of Dr Spock.” A BMJ review of the book’s third British edition proclaimed it a “masterpiece worthy of a place in every home.”

But Spock was not without detractors, including the influential US preacher Norman Vincent Peale and the conservative US vice president Spiro Agnew. They blamed his advocacy of “permissive” parenting for a “generation of hippies” and a general decline in morality. “At least,” Spock countered, “nobody could accuse me of having brought up Spiro Agnew.”

Spock’s advice has been blamed for medical as well as moral harms. For many years Baby and Child Care recommended that babies should sleep on their stomachs, a practice now known to increase the risk of sudden infant death syndrome. A review in the journal Epidemiology blamed such advice in “influential books” for “up to 10000 infant deaths in the UK and at least 50000” in the rest of the developed world. Its authors noted that the advice remained unchanged until well after persuasive evidence of harm was available.

Dr Spock’s childcare manual is the best selling book ever written by a physician. This feat is all the more remarkable because it was achieved without the book promotion blogs, podcasts, and Oprah appearances that characterise the contemporary era of celebrity doctor authors. First published in the United States in 1946, and never out of print since, the book famously assured anxious postwar parents that “you know more than you think you do.”

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The errr-portfolio

There was no need for a pipe, old school tie inspection, or back slapping. But punctuality, hard work, being pleasant, passing your exams, and conforming to professional norms saw doctors admitted to their chosen postgraduate specialty. However, these were the dark ages of the 1990s, and now education has “uniform validated assessments,” all overseen by expensive quangos full of Whitehall grantees and educational theorists. In general practice we have an online educational “e-portfolio”—now being rolled out to a specialty near you. Once you are past the control towers of Fortress NHS’s firewall and logging-on barriers, the electronic paper chase begins. There are 15 sectors, seemingly designed by 15 teams whose first language was not English, all held together by the electronic equivalent of a large ball of sticky tape. With more clicks than a Geiger counter in the Irish sea and more acronyms than a swine flu algorithm, here counterintuitiveness reaches a new level (even by NHS standards).

But once you have worked out your disguise, either as an educational supervisor or clinical supervisor, then come the electronic hoops. There is the COT (confusing observation tool), a dental extraction of qualitative feedback on consultation videos; the CBD (case boring discussion), discussing clinical cases in a painfully stilted way; the mini-CEX (no one actually knows what this means or how it is completed, but it seems to be related to the COT); the MSF (meaningless sourced feedback), which changes nothing but serves only to upset all concerned; DOPS (directly observed procedural skills), procedures supervised by doctors more junior than the trainee—“see one, do one, sign one off” is the new mantra; the PDP (perfectly dumb plan), a learning plan that everyone makes up two hours earlier and then ignores until two hours before the next annual assessment. Cleverly, the website’s “cut and paste” option has been disabled, for clearly the designers knew this temptation would be irresistible. The only sport is in writing tranches of educational spam, for the likelihood of anyone actually reading the entries is inversely related to the amount written.

The e-portfolio is micromanaging medical education. It is just doctors spending more time “recording” and less time “doing” education. So, to steal some educationalists’ phrases: it is time for needs assessment, a national plenary, or even some workshops with some frontline stakeholders. I am tired of this quasi-educational, didactic nonsense in the name of science.

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Where the heart is

Soon you’ll be free. You’ll shut the diary, activate the “out of office” email, and get away from it all for a fortnight. What have you got to look forward to (apart from the cancelled flights and lost luggage)? Well, there’s no more journal reading for a start; in fact, no reading at all, unless you count the novel that will end up as a face screen during the sunlounger snooze.

Now’s probably the worst time, therefore, to suggest that a recent research paper is worth looking at. Still, you might just have around 20 minutes to spare, so here goes.

The UK study in question assessed the anatomical knowledge of patients and the general public and found both grossly wanting (BMC Fam Pract 2009;10:43). The headline grabbing results made it into the mainstream press. But these are actually only part of why the article’s special.

Of note, too, the report is mercifully brief, well written, and modestly presented, with none of the typical statistics overload. And it’s good that the study was published in BMC Family Practice (an open access journal) and so is freely available to anyone through the internet. But it’s the direct relevance of the research questions and how these are addressed that really mark the paper out as a must read for anyone with an interest in communication between healthcare professionals and patients.

Who wouldn’t have believed that, compared with 1970, the general public today would be more informed about something as basic as the location of key body organs? Educational developments and the modern torrent of medical “infotainment” that issues from print, television, and the online media would suggest this. So it’s genuinely shocking to see that the study’s evidence crushes such assumptions. And even worse is the demonstration that many people with a disease related to a particular organ are not necessarily better than the general population in correctly locating that organ (with individuals with liver disease or diabetes being isolated exceptions).

The study’s findings also raise obvious further questions: if patients don’t know where an organ lies, why should they know how it functions? And if, in turn, that knowledge is poor, what basis is there for improving their understanding of more complex concepts, such as systemic body functions and how these may be altered by, for example, disease or drug treatment? These are intriguing, unsettling issues. And they should prompt many professionals to reconsider how they inform patients. But that can wait.

There are, after all, bags to pack.

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