



Reading round your therapeutic area

by Alison McIntosh

Often when you accept a medical writing job you begin the task by researching the therapeutic area concerned. This can mean a quick update to remind you of any changes, or researching for several days to try to get a feel for a new disease area. I often employ an additional method, which is effective, does not involve delving into text books, or surfing the net, and feels much less like ‘work’. Perhaps you already use it?

A while ago I found myself writing a couple of hundred very detailed case narratives for Parkinson’s disease. For large phase III studies this can involve trawling through many hundreds of pages of listings to extract key data points to populate narratives. In this instance, considering the amount of information required by the client, each narrative was taking over three hours to write, contained masses of information about drugs with unknown names, and procedures that were not familiar to me.

Writing narratives can be a very laborious exercise, and unsurprisingly deal with many negative aspects associated with a disease area. For me, to keep the task invigorating it can help to put the disease in context, not just from a scientific perspective, but also from a patient perspective.

To help me understand Parkinson’s disease from a patient’s view I began to read ‘Lucky Man: A Memoir by Michael J. Fox’ In his autobiography he deals with his career and also the discovery that he had young onset Parkinson’s disease [1].

He describes the symptoms of the disease first hand, writing, “Every time my most recent dose of Sinemet would wear off the disease presented me with a concise history of my symptoms—first the tapping of the pinkie, then the dancing hand, and within fifteen minutes or so, the whole of my left arm would be trembling. Tremoring, actually, is too subtle a word—the tremor would start my whole arm bouncing.” This kind of detailed description brought to life the ‘increase or worsening of tremor’ written in a listing as an adverse event.

Concomitant procedures undertaken during the course of the trial were also listed and in the book he describes having to undergo ‘thalamotomy’ providing a very detailed description of exactly what the procedure involved. This was no longer just a word written in a listing, and given a definition by a medical dictionary, but a complex procedure that patients underwent in an attempt to increase their quality of life.

In 1986 when I was investigating HIV-1 for my PhD, many new scientific discoveries were being made about a recently isolated virus. There were no licensed antiretroviral treatments and the outcome for those infected with the virus was considered dire. The media was full of extreme stories concerning HIV/AIDS and any celebrities reportedly dying from the disease. During this time I saw a performance of ‘Torch Song Trilogy’ by Harvey Fierstein [2] in a West End theatre. I remember I was incredibly moved by this seminal production which allowed the public examination of how AIDS had affected the gay community during the late seventies and early eighties in a more measured and productive fashion. It had absolutely no scientific content but what it did for me was place HIV-1 into a human context.

I know I am not alone in using personal accounts to help work through medical writing tasks. Last year I was asked to review oncology literature, a task I wanted to finish as quickly as possible. Another writer also assigned to the job approached the subject differently and began to read ‘Cancer: C: Because Cowards Get Cancer Too’ by John Diamond [3]. The author had been a journalist in the UK who recorded, in his newspaper column, his battle with throat cancer. This book recounts his life, his cancer and all the treatments he underwent and has very uplifting reviews on Amazon.

In the UK in recent months there has been much discussion around the outcome of the NICE review regarding availability of new dementia treatments. For those working in this therapeutic area who want to find out more about what this harrowing disease is like to live with on a day-to-day basis, John Bayley’s memoir would be a good place to start [4]. In this book he recounts the way normal life with his wife of 45 years slips further, and further away from him as the disease tightens its grip on her brain, ultimately destroying her ability to function as a person.

Interested in the moral issues science throws at us? Why not try reading the novel by Kazuo Ishiguro: ‘Never Let Me Go’. This book will leave you thinking about the moral dilemma of human cloning and all its implications [5]. Although not to be classed as a ‘light holiday read’ I thought it was an exceptional book.

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Where 'reading round your therapeutic area' is written from a very personal perspective, Anne Hudson Jones has written a series of academic articles on the contribution of literary narrative to medical ethics. If you would like to examine the moral and ethical issues this poses in greater detail then accessing the articles would be a pertinent place to begin [6].

Perhaps you have used this 'tactic' in reading round your therapeutic area? Do you have any recommendations? If so please let us know. Maybe we could post them on the EMWA website, or maybe we could start an EMWA 'book group' with discussions at each of the Spring conferences?...Or maybe I'm just a freelance medical writer who needs to get out more!

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6. A Hudson Jones. Narrative based medicine: narrative in medical ethics. *BMJ*. 1999 January 23; 318(7178): 253-256. (accessed 28 May 2007: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1114730>).

The *Lancet* published a special issue entitled 'Medicine and Creativity' in December 2006 (vol 328). This included an excellent article by Anne Hudson Jones on the beneficial effects of writing about illness (Jones AH. Essay Writing and healing. *Lancet* 2006;368:S3-S4). The article covers some of the well-established literature on patients' narratives of illness and is a helpful general reference to this literature.

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Oxymoron

The *Merriam Webster on-line dictionary* defines:-

Oxymoron: plural *oxymora*

Function: noun

Etymology: Late Greek *oxymoron*, from neuter of *oxymoros* pointedly foolish, from Greek *oxys* sharp, keen + *mos* foolish: a combination of contradictory or incongruous words (as *cruel kindness*); broadly: something (as a concept) that is made up of contradictory or incongruous elements.

Roget's Thesaurus does not list oxymoron in common every day usage. However, moron is listed as a person with a learning disability. Very recently oxymoron seems to have become an 'in' word. There was even discussion at the EMWA Spring conference about its meaning. Clearly some clarification is called for. Paul Dunne (pdunne@iol.ie) researched the word and found the daily

usage of the term oxymoron may refer to a person who, in trying to be clever, may end up appearing foolish in the presence of their peers. He found no reference to this possibility in a present day dictionary or other references. On asking people about their experiences with the word Paul collected the following examples:

wise fool	warm freezer	legal murder
plastic glass	adult children	good morning
pretty ugly	questionable answer	alone together
dangerously safe	fun run	civil war

With all deliberate speed (go quickly, slowly) Festina lente (Latin), hasten slowly
'So foul and fair a day, I have not yet seen.' (Shakespeare, Macbeth, Act I, Scene III).

Oxymoron is quite often used in jokes, e.g. 'military intelligence': intelligence (1) meaning intellect or use of brain, and (2) knowledge about enemy country. Another oxymoron joke might be 'honest politician', which implies there are no honest politicians!