



Patient-centred pharmacy: reflections from the patient-academic pharmacist interface

Ros Dowse, Faculty of Pharmacy, Rhodes University

Winner of the Best Academic Presentation Award at the SAAHIP Conference 2014

This month, the Pharmaceutical Society of South Africa (PSSA) pays tribute to a remarkable woman, who is willing to share her experiences with fellow pharmacists. Ros Dowse told her story at the South African Association of Hospital and Institutional Pharmacists and PSSA conferences, and will share it at the Academy conference as well. Ros, we are proud to be part of your "family", and are humbled by your courage and inner strength.

© Medpharm

S Afr Pharm J 2014;81(9):40-43

"When we are no longer able to change a situation, we are challenged to change ourselves."

– Victor Frankl, *Man's Search for Meaning*

Introduction

Over the past 2-3 decades, the pharmacy literature has described pharmacy as changing from a product-focused profession to a patient-focused one. Patient-centred care has received much attention in the medical literature, but how does it apply to pharmacy, and are we really a patient-centred profession? I will attempt to briefly explore these issues through my own personal "illness narrative".

Personal illness narrative

I have been an academic pharmacist at Rhodes University for almost 30 years. I consider myself to be an "expert patient", having had rheumatoid arthritis for 35 years, being diagnosed with and treated for extrapulmonary tuberculosis for 13 months, and having journeyed with oral cancer for 16 years. My experiences with the treatment and management of all of these conditions, but most particularly with oral cancer, stimulated me to question and reflect on many aspects of the "care" that I received from the various health professions.

After becoming aware of a tender spot on the right posterior area of my tongue in 1997, I was diagnosed with squamous cell carcinoma early in 1998. Between diagnosis and 2001, I had three occurrences of cancer and a total of four operations (tongue biopsies and excisions and right neck dissections of the lymph tree), as well as a six-week course of radiation.

The 2001 operation was my first fundamentally life-changing one, when almost half my tongue was excised and replaced with a vascularised flap from my left forearm, leaving me with altered appearance and functionality. Fortunately, after rehabilitation, despite speech difficulties, I was able to continue with my academic career.

Over the following nine apparently "cancer-free" years, I underwent extensive further treatment and prosthodontic work to prevent loss of the lower jaw due to post-radiation tooth decay, xerostomia and infections.

I never reached the magic 10-year, cancer-free target, as after extended periods of continuous oral candida infection, cancer was again diagnosed in 2010 just behind the lower front teeth implants.

Further biopsies and laser surgery were followed by a positron emission tomography scan which showed no evidence of cancer. However, the cancer recurred in 2012 in the same area. Results from extensive surgery revealed the presence of cancer in



Ros Dowse: academic



Ros Dowse: patient

Oral cancer journey

1997: Awareness of tender spot on posterior right side of tongue
1998: Tongue biopsy – diagnosis of squamous cell carcinoma
 Excision of portion of tongue; right partial neck dissection
 Six week course of radiotherapy (60 Gy)
2000: Excision of lump in neck; excision of portion of tongue; right radical neck dissection
2001: Hemiglossectomy; vascularized forearm flap to replace tongue

9 YEAR GAP IN ORAL CANCER OCCURRENCE

2005: Dentectomy and alveolectomy
 Hyperbaric oxygen treatment (30 dives)
2006: Dental implant placement in lower jaw; top teeth crowned

RECURRENCE OF ORAL CANCER - 2010...

2010: Excision of growth for biopsy from anterior floor of mouth
 Laser removal of tissue from anterior floor of mouth
2012: Resection of tumour – anterior floor of mouth and overlapping tongue

DIAGNOSIS OF CANCER IN JAW BONE AND SKIN

the jaw bone and around the implants, as well as in the skin over the jaw. This heralded the start of the traumatic, life-altering year of 2013.

A 12-hour operation kickstarted 2013, during which my jaw was removed, the fibula harvested from my leg was used to fashion a new jaw, and extensive microsurgery enabled blood supply to be provided to the fibula graft. So now I had my arm and my leg in my mouth, but as I joked to friends, at least I didn't have my foot in my mouth!

The three-week hospital stay was a traumatic one and a huge stimulus to me to start walking the path as a patient advocate to the health professions, as I constantly found myself wondering how seriously ill patients ever made it out of hospitals alive! I observed and experienced the very best, and unfortunately, the very worst, of hands-on "care", communication styles and (un) professional attitudes.

However, I considered myself to be fortunate, as being a health professional, I had high health literacy skills, plus I did not desist from pointing out errors, correcting nurses and demanding responses from doctors.

Despite this, there were times when I felt as though the health system had thrown me to the floor, and thoroughly and deliberately ground me to a pulp beneath its foot. But what about those patients who are less empowered or equipped to challenge the system?

I had two further operations in 2013 in an attempt to improve my seriously impaired functionality. I suppose that all of this life-changing surgery extended my life, but do I really want a life where people stare at me and where many of my basic functions are severely compromised? For example:

- I had to relearn how to swallow, and still have an impaired swallowing ability, often choking when eating or drinking
- My immobile tongue, in its fundamentally altered oral environment, cannot form a bolus of food so all food has to

Life changes forever...

December 2012
...last "normal" Christmas



January 2013 (12 hr op)
 Resection of malignant tumour
 Resection of anterior mandible
 Vascularised fibula graft to replace jaw

October 2013
 Partial release of tied tongue; sulcoplasty
 Implant placement
 Denture wired into "jaw"

And just as I thought things would improve with my next "minor" op

December 2013
 Extension of lower lip
 Loading of teeth

be soft and "mashed" with a fork, or else it must be liquid. My tongue also cannot work to "clear" my mouth of food, which, together with being unable to close my lips, means that food and liquid dribbles out, causing much embarrassment during speech. So where others blow their nose, I blow my mouth!

- My lower lip and jaw are numb and I don't have a normal sulcus so drinking always results in spillage.
- My speech is significantly compromised. It takes enormous physical and mental energy to try and form words. Talking to strangers causes embarrassment and attracts unwanted attention.

Patients in the healthcare system and in larger society

So where do overt functionality and disability issues place patients such as myself in society? How are we seen by "normal" people? Within our changed lives and selves, how do we cope with our compromised quality of life, answer the "big questions of existence", and try and make meaning of this new way of being within a wider social world? Sociologists study people in society and observe where and how individuals or groups, such as patients, fit into the "big picture".

In studying people with serious or chronic illnesses, sociologists often refer to "biographical disruption" in patients' lives. Sociologist Arthur Frank, in his book *The Wounded Storyteller*, writes:¹

"Serious illness is a loss of the 'destination and map' that had previously guided the ill person's life. Ill people have to learn 'to think differently'. They learn by hearing themselves tell their stories, absorbing others' reactions and experiencing their stories being shared".

He speaks to the disempowerment experienced by patients by saying: "Seriously ill people are wounded, not just in body, but in voice. They need to become storytellers in order to regain the voice that illness and its treatment often take away".

But what resonated so deeply within me, as a teacher, was his use of the term "the pedagogy of suffering" which he clarified as follows: "The one who suffers has something to teach...and thus has something to give".

Yes! We patients are not restricted to being passive recipients of care, but can also (if we choose) actively engage with society and make meaning of our experiences by teaching others, including our healthcare professionals. We have a choice.

As psychiatrist, neurologist and Holocaust survivor, Viktor Frankl (*Man's search for meaning*)² writes so profoundly: "Everything can be taken from a man but one thing – the last of the human freedoms, to choose one's attitude in any given set of circumstances, to choose one's own way".

A shifting focus in the treatment of patients

Increasingly over the past two or so decades, patients have started exercising this choice and forcing the shift to a more patient-centred approach in health care. Previously, the dominant model was biomedical, in which the focus was on professional knowledge of the disease and body part, with the role of the patient restricted to "complying" with instructions. This progressively silenced the patients' voices, leaving no place for "patients' illness narratives" that describe the lay experience of illness.

However, with the rise of chronic diseases in the mid-20th century, the single cause or curative focus of the biomedical model could not be applied to dealing with chronic disease.

Important markers in this paradigm shift include Engel³ in the 1970s, who proposed the biopsychosocial model, which takes into account the patient as a thinking, feeling, social being, as opposed to merely a body in need of repair.

The definitions of "illness" and "disease" by Kleinman⁴ in the late 1980s reflect the patient's subjective experiences, in marked contrast to the doctor's understanding of "disordered biomechanics". In the 1990s, increased accessibility to unlimited health information via the Internet narrowed the previously huge gap between "expert" and "lay" knowledge, and contributed to the rise of lay involvement in health care. The doctor is now no longer accepted as always "knowing what is best" in many situations as patients increasingly demand input into medical decisions.

Patient-centred care

In 2001, patient-centred care was enshrined by the US Institute of Medicine's (IOM) "quality chasm" report as one of six key elements of high-quality care.⁵ It is defined by the IOM as "an approach to providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions".

Patient-centred care speaks to the quality of personal, professional and organisational relationships and encompasses the obligation to care for patients who are listened to, informed, respected, known in the context of their own social worlds, involved in their care and treated on their terms.⁶ It does not centre around disease, doctors, hospitals, professional expertise or technology.⁷ Importantly, it does not comment on the skills and expertise of the health professional. That aspect is taken as a given.

So what does this term imply with regard to patient care from pharmacists? There is little clarity in the literature as to how this concept has been incorporated into commentary on the quality of care offered by pharmacists. National and international reports have alluded to patient-centred care, often altering it to patient-centred pharmaceutical care, and variously have:

- Encouraged pharmacists to "meet the changing needs of patients", "help patients to become better informed", to provide "counselling on disease prevention and lifestyle modification", and to adopt "shared decision-making on how to take medicines"⁸
- Explained to pharmacists that "the scope of pharmacy practice now includes patient-centred care with all the cognitive functions of counselling, providing drug information and monitoring drug therapy"⁹
- Informed pharmacists that "the demand for pharmacists' specialist skills in patient-centred pharmaceutical health care will grow markedly"¹⁰
- Defined the role of pharmacists as having "evolved from that of a provider of medicines to that of a provider of patient-centred pharmaceutical care"⁸

It appears that the philosophy that underpins the original concept of patient-centred care has not been appreciated by pharmacy organisations. Instead, it has been randomly incorporated by some into the controversial, contested term of "pharmaceutical care".

Are we clear about PCC in pharmacy?

- Has the term PCC been adopted and used in the pharmacy literature "consciously" or "unconsciously"?
- Has pharmacy explored the philosophy underpinning the original concept of PCC from its origins in the medical profession?
- Has pharmacy deliberately (mis)interpreted the term as it applies to pharmacy care?
- Where does "pharmaceutical care" fit in with patient-centred care?
- Is pharmacy aware of and happy with being the only health profession that has a different "take" on the term patient-centred care?

Personal experience of patient-centred care from pharmacists

As a patient, pharmacist input into my care, outside of Grahamstown, was as follows:

- I have never seen a pharmacist on the ward (16 operations)
- Dispensing was always accurate, and mostly efficient
- Problem-solving skills ranged from very good to embarrassingly non-existent
- Counselling was absent, apart from being provided with a quick rundown of the label instructions
- Attitude and demeanour ranged from friendly and caring, to unfriendly, with occasional rudeness
- Generally, there was a definite lack of humanity, warmth and caring. And where were the smiles?

However, I receive patient-centred care from my own community pharmacist who knows me and my health issues well. We have an excellent relationship. For me, it centres around the quality of relationships and the feeling of being cared for, heard and respected.

Given the wide range of settings and diverse roles and competency within pharmacy practice, we need to question if this practice is applicable to or desirable for all pharmacists working in all settings. We also need to acknowledge prior findings that not all patients actually want patient-centred care. I offer no answers, but in conclusion, I suggest that we should not adopt terms from other disciplines that have not first been fully conceptualised within the practice of pharmacy.

References

1. Frank AW. *The wounded storyteller. Body, illness and ethics*. Chicago: The University of Chicago Press, 1997.
2. Frankl VE. *Man's search for meaning*. Boston: Beacon Press, 1959.
3. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science*. 1977;196(4286):129-136.
4. Kleinman A. *The illness narratives: suffering, healing and the human condition*. New York: Basic Books, 1988.
5. Committee on Quality of Health Care in America, Institute of Medicine. *Crossing the quality chasm: a new health system for the 21st century*. Washington: National Academy Press, 2001.
6. Epstein RM, Street RL. The values and value of patient-centered care. *Ann Fam Med*. 2011;9(2):100-103.
7. Stewart M. Towards a global definition of patient centred care. *BMJ*. 2001;322(7284):444-445.
8. International Pharmaceutical Federation. *The FIP 2020 vision, mission and strategic plan*. FIP [homepage on the Internet]. c2014. Available from: <http://www.fip.org/files/fip/strategic%20plan%20no%20annexes.pdf>
9. Wiedenmayer K, Summers RS, Mackie CA, et al. *Developing pharmacy practice: a focus on patient care*. Handbook, 2006. FIP [homepage on the Internet]. c2014. Available from: <http://www.fip.org/files/fip/publications/DevelopingPharmacyPractice/DevelopingPharmacyPracticeEN.pdf>
10. Department of Health, UK. *Pharmacy in England. Building on strengths: delivering the future*. Department of Health, UK; 2008.