



Professor Jenny Carryer
RN, PhD, FCNA(NZ), MNZM
Executive Director

Recently I had the opportunity to attend the Cartwright Comes of Age seminar in Auckland. The seminar was held to mark the 21st anniversary of the release of the Cartwright report and was a forum for critical and consumer perspectives on the major themes and recommendations from the Cartwright enquiry.

One theme raised during the day was the realization that there will be a number of people working in health services now for whom the words Cartwright Enquiry may hold little meaning. Accordingly let me just bring any such readers up to speed. The Cartwright enquiry was convened in 1988 to investigate the management of women with abnormal cervical smears at National Women's hospital in New Zealand during the 1970s and 1980s. During this period Dr Herbert Green tested his theory that carcinoma in situ (CIS) was not always a precursor of invasive disease by constantly reviewing women rather than actually treating the disease. Most importantly women were unaware that they were essentially part of an experiment and many important issues such as informed consent

remained unaddressed. Some women died and many women were subjected to prolonged investigation and review.

Justice Sylvia Cartwright presided over the enquiry and produced a report, which was strongly critical of the care the women had received. The report recommendations have subsequently been responsible for our processes around ethical approval of research, the requirements for informed consent and the establishment of the Health and Disability Commissioner role and the Code of Rights. In addition recommendations stressed the need for care to become patient rather than provider centered and it was this theme that I was asked to address at the workshop and would like to share in this editorial

It has been said that to be sick or to be a patient is a situation of immense vulnerability. Whilst that is undoubtedly true and important twenty-one years later we might want to expand the notion of patient centeredness to consumer or people centered care but the principles or concerns remain the same.

In 1976 my experiences as charge nurse of an oncology ward made me very aware of the value of patient centered care. I was a very new charge nurse and the notion of oncology wards was previously rare. I established a number of processes which involved making it possible for families to be constantly present in the ward by providing food, spare camp stretchers or lazy boy chairs and making family members feel welcome and included. It was extremely gratifying to see the difference in patients who were thus supported.

Doing these things put the patient at the centre by meeting their needs regardless of institutional rules and strictures. My mother (as a registered nurse from the 1950s) found such practices quite unbelievable but went on to acknowledge the value and still speaks of her own unresolved anguish about the treatment of hospitalized children in her era. Parents were required to drop their very young child at the door and to return only when called to collect the child after a week or ten days or however long the admission was.

History has not had the patient at the centre and it is salutary to wonder how such cruelty could have been approved ostensibly on the basis of minimizing disruption to institutions and to health professionals

themselves. Patient centeredness is, as much as anything, a state of mind and our historical state of mind has been slow to reach that point.

In 1847 the first official Act of the American Medical Association was to adopt a code of ethics. The contents of that code which can be found on line were revealing. In the section on patient obligations it stated that

- 1) A patient should never weary his physician with a tedious detail of events or matters not appertaining to his disease.
- 2) The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them.
- 3) Never do anything about your own health care without consulting your physician

As per its time or era this Code of ethics captured a particular world- view. It also rendered women invisible. It is easy to see how such a world-view combined with the relative positioning of women in the world created a legacy whereby women especially could be treated in particular ways as they were at National Women's hospital. But we have now moved to a position post Cartwright and through the Code of Health and Disability Consumer rights where patient centeredness is central to our discourse meaning that at least we talk and write about it constantly.

There is now growing evidence to show that putting the patient at the centre of our thoughts and actions makes a difference to outcomes especially in long-term conditions and patient centeredness is now seen as central to the quality agenda. There is much talk about the expert patient and about shared decision making. The key principles are now largely accepted and they include the responsibility of health professionals to provide full information at all times and to involve people in decision- making in a transparent manner. Protection of dignity is of paramount importance and there is continual discussion about the need for and value of continuity of care

Sadly I am not sure we have moved very far beyond the rhetoric of "patient" centered care. Several

issues give me concern. Central to patient centered care and notions of the expert patient is the idea of patient's responsibilities. This is all very well but allows for potential tension arising between patient responsibilities and the possibility of patient (or victim) blaming. There is potential for this to be exacerbated by the resource-constrained environment, which is the current and future situation in health service delivery

Just recently we have seen the demise of the Primary Health Care Advisory Council seemingly triggered at least, by GP concern with a new service models package which the multi disciplinary Primary Health care Advisory Council had spent 18 months discussing, consulting, writing and approving. General Practitioner concern expressed by NZMA and RNZCGP members of the Council noted that in the new service model described there was insufficient importance attributed to the role of the GP in first contact care .

There is little notion of patient-centeredness in this decision and from my personal perspective it shows a strongly provider centric basis for decision-making. The service models package was very focused on patient centered care, on issues of access and of planning for a current and future context where GP availability is very scarce in many areas.

On a different note (but equally importantly) much research over the last 20 years shows that nurses who have long been educated in a patient or rather person-centered framework have absorbed and adopted the dominant provider centric ethos within months of commencing practice; largely as a survival mechanism. It is interesting to see how much they regain that focus when they work in certain environments such as a hospice, which are by their very nature people, centered.

Patient centered care is both an attitude and a practice focus and it is hard to say which one comes first?? Currently I think our structures and funding and leadership models continue to favour a medical model of care and leadership rather than a patient centered model. There is a self-fulfilling circuitous process in place in which attitudes and beliefs shape our infrastructure and our infrastructure shapes our attitudes and practice. There is a huge amount of work to be done before the rhetoric of people or patient centered care becomes our reality.