

Practising Within an Ethic of Care

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Nurses are privileged to share with their patients some of the most significant and often traumatic times in their lives. At these times nurses are



faced with ethical dilemmas and decisions unlike others in health care. This is as a direct result of the unique place nurses have in the health care system and the unique relationship nurses develop with patients and their families. Nurses' stories make visible the richness of nursing practice, and show their differing perspective on moral issues and ethics. A nursing ethic, the ethic of care, is emerging as a perspective that fits well with nurses' moral experience.

An ethic of care, such as in nursing, favours subjective thinking and reflection, and allows time and space for seeing and feeling. The nurse in the following story captures this idea as she describes caring for her patient. This story is a true story, told by a nurse who values the difference her caring practices can make in the lives and the deaths of her patients and their families.

"It was 3.45 pm. An anxious staff nurse had bleeped me and asked me to come now. She explained that one of her patients, Sue, had started faecal vomiting, and her spasmodic abdominal pain was getting worse. I was the senior nurse on the recently formed support team, caring for patients referred for help in the terminal stages of their illness. I had been involved with Sue since her consultant decided that the advanced stage of her disease might necessitate more detailed symptom control and support than was usually available. Sue had now developed obstruction of the large bowel which was irreversible.

I needed to help her understand what was happening to her body, gently and without causing fear. More importantly, I had to offer hope, maintain her quality of life and help her retain a feeling of being in control within the limitations of her disease. Sue had undergone extensive pelvic surgery three years earlier for an ovarian tumour. Even after widespread recurrence she always displayed a stoical front for the benefit of her husband and two sons.

When I had first met her a year earlier, she had been an attractive, confident young woman. In spite of evidence of advanced disease she had managed to work part-time as a secretary and run her home.

Many questions ran through my mind as I thought of all that Sue had been

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through and knowing what was likely to come. Did she still have choices? Could she still remain independent and autonomous as she always had been, even at this late stage?

As I sat on her bed, I wondered what was going through her mind. Could she feel my pain as I desperately tried to find the right words to tell her that death wasn't far away? It was as if I was looking at myself in a mirror and seeing a woman, still young and very much wanting to live.

I told her: "We can help your symptoms, Sue, and we can almost certainly get rid of the pain. We may not be able to stop the vomiting completely but it doesn't have to be as often as this, and we can stop the nausea".

There was so much I knew we needed to discuss and share. I continued: "Tell me how you feel at the moment? What is worrying you the most? What does the pain feel like: sharp, dull, burning?"

But the silences in between the questions seemed endless and my mental pain intensified.

Suddenly she drew me closer. "This must be awful for you, love, telling me that I'm going to die". No more words were needed. Tears flowed between us. The understanding was total. She, in turn, was able to ask those things that she really wanted to know: "How long have I got? Does my husband know? What will the boys do when I'm gone? I am frightened, yet relieved that I don't have to pretend anymore. It will be easier now, won't it? Will you be there when I talk to my family? We then discussed how we would use a subcutaneous syringe driver to control her symptoms and decided she should have a nasogastric tube.

During that next week she had eggs and bacon, strawberries and ice cream, even though she could not swallow them, and she stayed pain free, with minimal vomiting. She even went home for a day to say goodbye and sort out her affairs, and died peacefully one week after developing the obstruction.

I think the hardest thing for health care professionals to understand is that when communicating with the dying there are no special words. If only we could see ourselves first and foremost as human beings, as frail and vulnerable as our patients, and acknowledge their pain, rather than try to find an answer. Sue understood better than I that it was my pain that caused me to spend nearly 40 minutes trying to find the right words to tell her she was going to die. It was she who supplied those words before I could find them myself.

Sue's ability to support me during her final week helped me more than any amount of reading, to understand the need not to hid behind the anonymity of professionalism, but to reach out and meet our patients as fellow human beings."

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This is a powerful story. What we need to do is uncover from this nurse's story how she was able to maintain the ethic of care in her practice.

The process

There are several themes emerging as central to the ethic of care. The first of these is the idea of process.

For nurses, although outcomes are of vital importance, the process is just as important. If death is inevitable, then how a person dies matters to nurses. The nurse in this story knew that Sue was going to die and it mattered to her how this happened. As she herself said, it had taken her forty minutes trying to find the right words to tell Sue she was going to die. She made sure that Sue was able to ask those things that she really wanted to know. And she made sure Sue's last weeks were pain free, with minimal vomiting, and filled with what Sue wanted, within her limits. It was important to this nurse that Sue would understand what was happening to her body without causing fear, and that Sue would retain a feeling of being in control. For nurses, ensuring a good outcome is dependent upon the process. The literature is just beginning to support this idea. However from talking to nurses, and from my own experience, I believe it has to do with it being a deeper professional relationship that develops between the nurse, patient and their family than is commonly acknowledged.

Nurse/patient relationship

The relationship the nurse develops with her patient and their friends and family is central to the ethic of care. The bond between the nurse and the patient is unique and so places nurses in a privileged position with the patient which must be acknowledged and valued if faced with ethical decisions.

Sue's nurse felt pain for the woman she saw in front of her as she searched for the words to tell her of her imminent death. This nurse talks about how much there was to discuss and share, and that when finally Sue herself acknowledged how difficult it must be for this nurse to tell her she was going to die, they cried together. No words were needed, and the understanding was total. The story begins to capture the complexities of the nurse/patient relationship, a relationship which is often as reciprocal as this one described. Sue and her nurse shared together. Sue supported this nurse during her final week, and as

patients often do, she taught this nurse something invaluable, the need for us to reach out and meet our patients as fellow human beings.

Importance of the Context

In order to do this, nurses develop an understanding of their patient's context. The context describes all the ways a person is connected in the world. To every situation people bring unique experiences and understandings that have been shaped by their past. In telling her story Sue's nurse felt it important to include some detail about how Sue had coped in the past, that she had displayed a stoical front for the benefit of her husband and two sons. This gives us another dimension to Sue's character, and it shows us in one way how this nurse had a good understanding of Sue's context. This story expresses how important it is that Sue maintains her independence and autonomy - and we get the feeling that this nurse knows how important these things are to Sue, how they matter to

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her. Situations are informed by meaning and they will be different for every person. These meanings are influenced by culture, and how a person understands the world, by the concerns people have.

As Sue's nurse demonstrates, in an ethic of care it is acknowledged that people live in the world in an involved way, not the subject/object way that we might have been led to believe. Nurses too are involved in this context. Nurses spend 24 hours a day caring for patients on an intimate front line basis. It would be wrong, in fact impossible, for them to divorce themselves from the concern they have for that person and the context. The nurse, like Sue's nurse, is an inextricable part of the situation.

Interestingly, this has often been given as a reason why nurses are unable to play a part in moral decisionmaking and discussion - because they are too close to the situation and inclined to be emotional. The ethic of care would suggest that these things are an essential part of moral deliberation.

Acknowledging vulnerability

Nurses are well aware of the power structures within health care settings - particularly large institutions - and the

resulting powerlessness that patients and their families experience. This powerlessness creates a vulnerability within patients and their families.

As this nurse told her story we could feel Sue's vulnerability, her questions, the uncertainty. What would happen to her family once she was gone, and what lay ahead for her in the days and weeks to come?

The ethic of care, therefore, is the commitment to alleviating another's vulnerability. Care becomes the ethical principle by which all interventions are measured.

"Only in the context of care, can the overpowering of one person by another, that cure [treatment] entails, be redeemed and thus relieve the person's vulnerability."

(Gadow, 1988)

The nurse too is vulnerable in care for people, as Sue's nurse acknowledges. She says "if only we could see ourselves first and foremost as human beings, as frail and vulnerable as our patients". All through her story we can feel this nurse's vulnerability too. The fact she is able to acknowledge this, and not try to fight it or suppress it, enables her to reach out and hold on to Sue in her vulnerability. The vulnerability creates a chasm between the nurse and the patient, and crossing this chasm is the only means of relieving this vulnerability.

"The greatest ethical task of the nurse is reconciling those two extremes, maintaining a relationship in which the chasm is never uncrossable, where no assault is permitted unless it can be redeemed, not by its future effect but by the immediate, present caring of the nurse, who because she has not let go of her own vulnerability is able to reach across the chasm and hold on to patients in their vulnerability."

(Gadow, 1988)

The possibility for alleviating patients' vulnerability is destroyed when nurses become invulnerable. This is often what nurses do in order to cope in this rapidly changing health care system. When this happens care becomes impossible and efforts to cure outside the context of care are unethical.

The 'Privileged Place' of nursing

The nurse who had the courage to tell this story, makes explicit how the 'privileged place' of nurses gives them a unique perspective on moral issues, and that the moral dimensions of care must be valued and taken seriously.

For nurses, it is the day to day encounters that make the difference in their patients' lives. In the course of their daily work nurses are faced continually with moral conflict. Their conflicts centre, not so much on the life and death decisions so oftensensationalised, but the human side of that. A nurse once captured this idea when she said that nurses often 'pick up the pieces'. It is this idea that is rooted in an ethic of care. Rather than the situation being a dilemma or crisis in which one must deliberate or choose, the emphasis is moving to morality as a way of being in a relationship with others, much as is demonstrated by the nurse in the story. An ethic of care determines how that relationship will be, and it is this which enables nurses to work through the many complex issues in health care with patients and their families.

Fry (1988) suggests the 'Ethic of Care' serves as a universal value that guides nursing practice. It is my contention that without an 'Ethic of Care' to guide nursing practice, all else becomes unethical.

References

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Gadow, S (1988) Covenant Without Cure: Letting Go and Holding on in Chronic Illness. In Watson, J., and Ray, M.A. (Eds.) *The Ethics of Care and the Ethics of Cure: Synthesis in Chronicity*, pp 5-14. New York: National League for Nursing

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New Journal:

Health Care Analysis

A new journal has just been added to the rapidly expanding list of those in the Bioethics field. *Health Care Analysis*, subtitled "Journal of Health Philosophy and Policy" is edited by David Seedhouse of Auckland Medical School. The first issue (published in June 1993) contains a good range of papers on priorities and health reforms, including ones on Oregon, New Zealand and Oregon, plus several other features. Columns on Nursing Analysis, Health Care Law and Teaching Analysis will be of interest to many of our readers. The editorial board and authorship shows a good interdisciplinary and international scope. Authors in this first issue include Stuart Spicker from Texas, Henk ten Have from the Netherlands and Ruth Chadwick from Wales.

Subscription information from:

Rachel Foster, *Health Care Analysis*, John Wiley and Sons Ltd, Baffins Lane, Chichester PO19 1UD, United Kingdom.

Establishment of Working Party

The possibilities for clinical and research use of human genes are expanding rapidly. The Health Research Council has established a working party to review existing practice and guidelines in the use of human genes, to identify use of human genes in organisms, and to prepare draft guidelines on their clinical and research use. Once prepared, the draft guidelines will be available for public consultation.

Membership of the working party reflects the range of concerns (scientific, ethical and structural) which need to be addressed. Dr J. Gough (risk assessment) has been elected Chair. Other members are Professor D. Bullock (biochemist), Professor A. Campbell (ethics), Professor P. Bergquist (cellular and molecular biologist), Dr A Moeed (Ministry for the Environment), Dr J Dixon (clinical genetics), Dr B. Scoggins (HRC), and Dr G Keating (Ministry of Health). Mr M. Stenersen is the Secretary of the working party.

Cultural and Intellectual Property Rights

In June 1993, the Nine Tribes of Mataatua in the Bay of Plenty Region of Aotearoa New Zealand convened the First International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples.

Over 150 delegates from fourteen countries attended, including indigenous

representatives from Ainu (Japan), Australia, Cook Islands, Fiji, India, Panama, Peru, Philippines, Surinam, USA, and Aotearoa.

The Conference met over six days to consider a range of significant issues, including; the value of indigenous knowledge, biodiversity and biotechnology, customary environmental management, arts, music, language, and other physical and spiritual cultural forms.

On the final day a Declaration was passed by the Plenary and has subsequently been signed by 100 further people from over 60 countries.

Further information can be obtained from the International Association of Mataatua Declaration, PO Box 76, Whakatane.

The Interim Taskgroup on Health and Disability Services Ethics

The Director-General of Health has now appointed the *Interim Taskgroup on Health and Disability Services Ethics*. This taskforce will examine the current structure and working of Ethics Committees rolled over from the previous Area Health Boards and make recommendations to the Ministry about the proposed National Advisory Committee on Health and Disability Service Ethics.

The task group comprises:

Maria Brucker who has been contracted by the Ministry to be project manager; Jan Crosthwaite who is a philosopher and member of the University of Auckland Ethics Committee; Grant Gillett from the Otago Bioethics Centre;

Sharon Kletchko who is Clinical Director, Emergency Services, Western Bay Health, Tauranga;

Regina Peretini, Ngati Kahungunu, who works for the Public Health Commission and is on the Wellington Ethics Committee and the HRC Maori Committee;

Gaye Payze who is Ethics Analyst for the Ministry of Health; and

Hohua Tutengaehe, Matawaka, who is the Kaumatua for Christchurch Polytechnic and also on the HRC Maori Committee.

This group met on 30 August. The task group has a close time frame with an initial report on the National Standard and interim arrangements by 30 October 1993, and a final report by February 1994.