

Australian Guidelines for Human Research

This article explores the new National Statement on Ethical Conduct in Human Research.

We all benefit from medical research. As well as providing new treatments, research allows us to discern what is best practice for existing treatments. Hospitals and aged care homes who are concerned about quality care therefore rightly invest funds, expertise, time and energy into research.

In Australia, most research is conducted in accord with the guidelines of the *National Statement on Ethical Conduct in Human Research*. A new version of this statement was released in March 2007.¹ As its name implies, it considers not just medical research, but all research which involves human beings. It was developed jointly by the National Health and Medical Research Council (NHMRC), the Australian Research Council, and the Australian Vice-Chancellors' Committee (now Universities Australia). It replaces a similar statement which had been released in 1999.² (I shall refer to these two statements as NS 2007 and NS 1999.)

I offer eight comments about this Statement:

Firstly, the 2007 Statement provides a better account of its **purpose** than did the 1999 Statement. The 1999 Statement identified both a primary and a secondary purpose. It said that the primary purpose of the Statement was "protection of the welfare and rights of participants in research," whereas its secondary purpose was "to facilitate research that is or will be of benefit to the researcher's community or to humankind." (NS 1999, p. 1) This account tended to encourage those responsible for the ethical assessment of research to look at researchers with some suspicion - as if they would violate the welfare and rights of research participants, and it was our primary task to stop them. By contrast, the 2007 Statement identifies a single, overarching purpose, which in turn involves two separate requirements. Thus, according to the 2007 Statement, its purpose is "to promote ethically good human research." This in turn requires both that "participants be accorded the respect and protection that is due to them," and "the fostering of research that is of benefit to the community." (NS 2007, p. 7) The difference may be subtle, but it

reminds both researchers and those responsible for the ethical assessment of research that we all share the task of promoting good research.

Secondly, the 2007 Statement offers an explanation of **why** there should be such a National Statement. Several answers are provided. For example, under the *National Health and Medical Research Council Act 1992*, the NHMRC has a statutory obligation to issue guidelines for medical research, and compliance with the Statement is required for all medical research funded by the NHMRC. But above all, the justification is that members of the Australian community become involved in research. It is therefore important that research is performed in ways that are "ethically acceptable to the Australian community." Indeed, there is a "public responsibility" to ensure this. It is for this reason that the content of the National Statement "reflects the outcome of wide consultation with Australian communities who participate in, design, conduct, fund, manage and publish human research." (NS 2007, p. 4)

Thirdly, the **ethical framework** of the Statement moves from values to principles to guidelines. The Statement identifies four values which must shape research. These are respect for human beings, research merit and integrity, justice, and beneficence. While these "are not the only values that could inform a document of this kind," these four

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values “have become prominent in the ethics of human research in the last six decades.” (NS 2007, p. 11) These values become specified as principles, which are general statements arising from the values. In turn, the principles become specified as guidelines, which are more specific statements. Thus, for example, the value of justice is partly specified by the principle that “there is no exploitation of participants in the conduct of research” (NS 2007, 1.4e), and further partly specified by the guideline that care should be taken not to over-research those who are vulnerable to such over-researching. (NS 2007, 4.3.4) This ethical framework is generally used to organise the National Statement.

Fourthly, this framework means that the ethics of research is more than simply keeping certain rules. More fundamentally, the ethics of research must arise from an ethical **attitude** within the researcher which informs an ethical **culture** or **ethos** within the research community. Thus, the 2007 Statement comments that “‘ethical conduct’ is more than simply doing the right thing. It involves acting in the right spirit, out of an abiding respect and concern for one’s fellow creatures.” It adds that the Statement “is therefore oriented to something more fundamental than ethical ‘do’s’ and ‘don’ts’ – namely, an ethos that should permeate the way those engaged in human research approach all that they do in their research.” (NS 2007, p. 3)

Fifthly, the **content** of the National Statement is divided into a User Guide, a Preamble, comment on the Purpose, Scope and Limits of the document, and five main Sections. Section One explores the values which inform good research. Section Two discusses important themes in research ethics, including the assessment of risk and benefit, and the seeking of informed consent from research participants. Section Three presents ethical standards relevant to specific types of research, including clinical drug trials, tissue banks, and genetic research. Section Four explores ethical issues relevant to various types of research participants, including children and young people, people with various disabilities, and Aboriginal and Torres Strait Islander peoples. Finally, Section Five sets out accepted processes for ethical review and research governance.

Sixthly, there are significant **changes in content** from the 1999 Statement. At one level, this means that whole chapters have either been deleted or added. For example, Chapter 10 from the 1999 Statement on Research Involving Ionising Radiation has been deleted as this research is now managed by the Australian Radiation Protection and Nuclear Safety Agency. And Chapter 11 on Research Involving Assisted Reproductive Technology has been deleted as the NHMRC has separate guidelines for this type of research in *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004*.³ On the other hand, there are new chapters

in the 2007 Statement on Risk (NS 2007, 2.1), Qualitative Methods (3.1), Databanks (3.2), Human Stem Cells (3.6), Women who are Pregnant and the Human Foetus (4.1), People who may be Involved in Illegal Activities (4.6), People in Other Countries (4.8), and Institutional Responsibilities (5.1).

In my opinion, it is particularly significant and helpful that the new National Statement includes a chapter on Qualitative Methods. Whereas quantitative research often focuses on the treatment of physical disease, such qualitative research “involves disciplined inquiry that examines people’s lives, experiences and behaviours, and the stories and meanings individuals ascribe to them. It can also investigate organisational functioning, relationships between individuals and groups, and social environments.” (NS 2007, p. 25) As the Statement indicates, qualitative research has its own methodologies.⁴ Sadly, these are not always well understood by hospital-based Human Research Ethics Committees (HRECs). The new Statement will go some way to address this. However, I wonder whether every HREC should also ensure that it has a member or at least a consultant with expertise in qualitative research methods.

As well as the inclusion or exclusion of whole chapters, there are many smaller but nonetheless significant changes in the new Statement. In the main, these reflect evolving standards as we learn from experience or as we address previously unrecognised problems. I offer three examples. First, consent for future research may be specific, extended, or unspecified. Specific consent is limited to the existing research project; extended consent permits similar projects; and unspecified consent permits any ethically approved research. (NS 2007, 2.2.14) Now, the 1999 Statement was generally hesitant to allow anything but specific consent. For example, with human tissue samples, it required that consent “be specific to the purpose for which the tissue is to be used.” (NS 1999, 15.5b) By contrast, the 2007 National Statement allows for specific, extended and unspecified consent for data banks (NS 2007, 3.2.9c-i), human tissue samples (NS 2007, 3.4.7), and genetic research (NS 2007, 3.5.7a-ii). In that the 1999 position excluded choice, whereas the 2007 simply permits people if they choose to give either extended or unspecified consent, this seems a reasonable advance.

Second, in recent years there have been concerns that some pharmaceutical companies might not publish results which are unfavourable to the drugs that they are developing. Thus, the 2007 Statement requires that researchers seeking ethical approval must reveal if there are any restrictions on publication (NS 2007, 3.4.4c), and particularly that any payments from the pharmaceutical company will not influence publication. (NS 2007, 3.3.5b) Further, it requires clinical trials to be registered in a publicly accessible register, most of which monitor publication. (NS 2007, 3.3.12) This is a welcome advance.

Third, as regards people with a cognitive impairment, intellectual disability, or a mental illness, both Statements recognise that sometimes consent will have to be given by someone other than the impaired person. (NS 1999, 5.2b; NS 2007, 4.5.5) However, the 2007 Statement also requires that in such cases “the researcher should nevertheless explain to the participant as far as possible, what the research is about and what participation involves.” (NS 2007, 4.5.8) Again, this is a reasonable development.

Seventhly, the new National Statement is intended to bring about significant changes in **research governance**. Such research governance is “the framework by which institutions support, monitor and attest to the safety, ethical acceptability and quality of the research they undertake.”⁵ There are currently two major difficulties here which the Statement seeks to remedy:

First, some institutions might not be fulfilling all their responsibilities for research governance. Instead, they may expect their Human Research Ethics Committee (HREC) – or its secretariat – to do everything. And despite these expectations, they may not have provided adequate resources to their HREC.

The new Statement emphasises that the institution itself is ultimately responsible for the research which it conducts. It is an institutional responsibility to ensure that research is designed and conducted properly, and that it is ethically reviewed and monitored. (NS 2007, 5.1.1, cf 5.7.3) Thus, “institutions should use and promote clearly formulated, documented, accessible and current policies and procedures for research governance and ethical review.” (NS 2007, 5.1.5) The Statement continues with guidelines for many areas of research governance. These include processes for ethical review (NS 2007, 5.1 & 5.2), minimising the duplication of ethical review (5.3), managing conflicts of interest (5.4), monitoring research (5.5), and the handling of complaints (5.6).

Will institutions respond to the challenge of the new Statement? It remains to be seen.⁶ If the opportunity is grasped, two areas are most important. First, institutions need to dedicate more resources towards education and training in research ethics. Such education should particularly target both researchers and HREC members. And second, more resources should also be directed towards the monitoring of research. One strategy here would be to appoint a suitably qualified person to monitor research for a certain number of hours each week.

The second current major difficulty is that many HRECs are overworked. The new Statement seeks to reduce this workload by authorising other processes of ethical review. It defines both low risk research “where the only foreseeable risk is one of discomfort,” and negligible risk research where “any foreseeable risk is no more than in-

convenience.” (NS 2007, 2.1.6 & 2.1.7) It permits that low risk research could be reviewed by some process other than a HREC, and that negligible risk research could be exempted from ethical review. (NS 2007, 5.1.7 & 5.1.8) Hopefully, such initiatives will reduce HREC workload, and therefore enable HRECS to concentrate on those research protocols which really do need rigorous ethical review.

Eighthly, note that some research permitted by the new National Statement could **not** be conducted at **Catholic institutions**. This is because Catholic institutions must also conform to Catholic morality, including the guidelines of Catholic Health Australia’s *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*. An obvious example is research involving human embryonic stem cells, which the new National Statement considers in Chapter 3.6. For those who work in other institutions, it is pleasing that the new National Statement recognises a right to conscientious objection whereby those with such objections “should not be obliged to participate, nor should they be put at a disadvantage because of their objection.” (NS 2007, 3.6.7)

The new National Statement is a significant advance. Of course, it too is only a step on the way, and it too will ultimately be revised in the light of new insights. To facilitate this, the new Statement has been published in a loose-leaf format so individual chapters or sections can be revised and re-issued without replacing the entire Statement. But even allowing for future advances, the new National Statement on Ethical Conduct in Human Research is a most important step forward in the oversight of human research in Australia.

ENDNOTES

¹ This Statement can be viewed online at http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf

² For discussion of the 1999 Statement, see Tracey Phelan, “National Statement on Ethical Conduct in Research Involving Humans,” *Chisholm Health Ethics Bulletin* 5:1 (Spring 1999), 1-4.

³ These Guidelines can be viewed online at <http://www.nhmrc.gov.au/ethics/human/issues/art.htm#2>

⁴ For helpful comment on this, see J Daly, K Willis, R Small, et al, “Assessing Qualitative Research in Health – A Hierarchy of Evidence-for-Practice,” *J Clin Epidemiol* 2007: 60, 43-49; and J Daly and J Lumley, “Dilemmas in Publishing Qualitative Public Health Research,” *Australian and New Zealand Journal of Public Health* 31:3 (2007), 203-204.

⁵ WP Anderson, CD Cordner and KJ Breen, “Strengthening Australia’s framework for research oversight,” *Medical Journal of Australia* 84:6 (2006), 261-263 at 262.

⁶ Deborah Frew and Ainsley Martlew comment that this recognition of research governance is “potentially the most significant advance in the Australian research ethics environment for several years” and “our best opportunity to improve the functioning of the HREC system.” However, they caution that only “time will tell” if this opportunity is indeed taken up. For this, see D Frew and A Martlew, “Research Governance: New Hope for Ethics Committees?” *Monash Bioethics Review* 26:1-2 (2007), 17-23 at 18 and 23. Similarly, Giuliana Fuscaldo suggests that these developments “are an important step in

strengthening research oversight,” but that “it remains to be seen how institutions will respond.” For this, see G Fuscaldo, “Editorial,” *Monash Bioethics Review* 26:1-2 (2007), 1-4 at 2

and 4.

Kevin McGovern



Beyond Informed Consent – Part I

One of the tensions touching the physician - patient relationship today is the physician's ability to correctly interpret what the patient psychologically and emotionally needs from the medical consultation following the diagnosis of chronic or serious illness. The analysis of the issue goes beyond the concern of what information is given to a patient and begins with the importance of good communication.

Summary of Issue

The ethics of medical consultation deserves wider consideration than the traditional domains of medical process and outcome, and medicolegal standards for professional accountability. Arguably, the management of a patient's chronic disease necessitates more than merely managing the patient's symptoms and needs for treatment. Whilst this would nominally be accepted by all practitioners, highly specialised and technological medical approaches to disease management means attention to communication habits with patients can become a dynamic of patient care that is increasingly muted against other competing demands.

It could be that time taken to reflect upon the patient's experience may bring to the forefront tensions that are unpredictable and not easy to resolve. From the patient's perspective, aligning treatment options with preferred personal outcomes is not an easy task, especially where outcomes are irreversible or uncertain and timing is both crucial and pressured. The Cancer Council of Victoria substantiate that a common problem for cancer patients is a perceived lack of adequate time to process complex information.¹ The National Breast Cancer Centre also states ‘many people report inadequate information to guide decision-making, and others are disadvantaged because of a lack of knowledge about practical support, even when such services are available.’² This presents a significant ethical challenge for physicians in particular, in delivering the best medical care that not only conforms to clinical excellence, but also humanely engages the patient at their level of expressed need.

The question of how to give patients the time and support they need is not readily considered by physicians, but an examination of this question is necessary. This prompts consideration of four ethical domains interfacing patient decision making: the significance of good communication; what does being patient centred mean; barriers to patient participation in decision making; and recommendations for an ethical approach to decision making support. A synthesis of these issues will inform discussion on the importance of engaging patients in a decision making style that is individually tailored to their needs, so that understanding informs desirable personal choices, whether they

be regarding treatment, intervention, surgery or palliation.

Good communication

In the management of chronic health conditions, consultation with the medical specialist is a strategic time where clinical progress is analysed, assessed and monitored. The process of medical consultation, sometimes only because of the extent of its importance to patients, and the urgency to make the right medical choice(s), can be stressful. Difficulty coping with the management of disease can also be a product of the patient's vulnerability. Patients may not have the personal experience, stamina or English literacy to manage complex information, adding pressure or a general sense of unease with the situation in light of the choices that need to be made. Also, on any given pathway of life, however well accomplished, people can be poorly equipped to cope with serious, unexpected downward spirals of personal circumstance. When things are going well, there is simply not often the desire to contemplate that things may one day be different. It is often from such a disposition that patients embark on the management of their complex health problems. Furthermore, treatments often significantly impact the patient's quality of life, at least in terms of side effects and experience of symptoms, as well as from the pressures emanating from living with the disease, its management and associated risks. The National Breast Cancer Centre reports that ‘up to 66% of people with cancer experience long term psychological distress: up to 30% experience clinically significant anxiety problems, and prevalence rates for depression range from 20% - 35%.’³

It is not possible to address the question of how to properly support patients in decision making, without first giving consideration to the importance of good communication. Good communication can be highly subjective to define, but its absence is noticed acutely by patients. Here, good communication is defined as communication that simultaneously respects the dignity of the patient, is responsive to the needs of the whole person, and meets all the expectations contained in the guidelines for informed consent by the National Health and Medical Research Council (NHMRC), where it is appropriate to do so.

There is a special relationship between the physician's

dedication to good communication, and the patient's perception of the empathy, compassion and sense of connection with the physician. It is not necessary to support this assertion with research evidence, because at different times it is a general truth that we have all felt, or wanted to feel. Historically, empathy, compassion and a sense of connection that culminate in a relationship of trust have not been associated with clinical outcomes per se. Similarly, it is only in the last ten years in Australia that psychosocial guidelines have been published in relation to cancer care, a move which placed the importance of a cancer patient's emotional wellbeing on the policy agenda.⁴ But a growing body of evidence now shows that a physician's success in reaching out to patients is actually of high clinical relevance. Fiscella et al summarise, 'physician trust has extrinsic value because it has been linked to patient satisfaction, adherence to treatment, continuity of care with the same physician and improved health.'⁵

Similarly, it is also now well established that attention to the issue of how patients absorb and make sense of complex information, not only has an impact on how they feel about the consultation, but on clinical outcomes. A snapshot of examples of patient misunderstanding over the last ten years demonstrates the importance of these linkages. Schofield et al conducted a study at a major tertiary teaching hospital in Sydney to examine what contributes to 'on the day surgery cancellations.'⁶ They found 'communication failure' was the reason 7 patients did not present for surgery in a six month period in 2002.⁷ Having a degree of control over important treatment decisions is important, particularly where the disease being treated is life threatening. Lobb et al advise from Sydney in 1999 'our results support the hypothesis that it is misunderstanding, not denial, that causes confusion. A considerable number of women in our study did not clearly understand some of the language used to describe the risk of breast cancer recurrence after surgery or how additional treatment might benefit them.'⁸

The University of California, San Francisco, refer to a study by Schillinger and Machtinger who 'found that nearly one half of patients on anticoagulants were not taking their medication accurately, but did not realise it. When describing the dose and frequency of the medication, patients and doctor often had two completely different understandings.'⁹ Warfarin, the medication referred to in the study, is a popular drug used to prevent blood clotting such as occurs in thrombosis, and to control the risk of a heart attack or stroke caused from atrial fibrillation. Non compliance with the directions for this medication is a major contraindication listed for warfarin, due to the need to carefully monitor serology levels to prevent risks of haemorrhage or stroke.¹⁰ Borosak, from the Alfred Hospital, Melbourne, advised 'almost 1.9 million out-of-hospital prescriptions for warfarin were dispensed in 2001.'¹¹

The University of California, San Francisco report that Schillinger and Machtinger found people who were particularly susceptible to misunderstanding included 'patients with limited literary skills, those for whom English was not their first language, and those with memory problems.'¹² A range of demographic characteristics of the Australian population substantiates the likelihood that these findings are also relevant for consideration in Australia.¹³

The Australian Bureau of Statistics (ABS) 2007 Year Book of Australia reports that of people born in Australia 'who speak a language other than English at home', 76,855 people either do 'not speak English well', or do 'not speak English at all', and this figure increases to 518,236 for the total population.¹⁴ The NHMRC refers to ABS data from 1996 which shows that in reference to Australian adults: 19.7% had 'very poor literacy skills with considerable difficulty using printed materials encountered in daily life.' 27.5% had 'some difficulty in using printed materials encountered in daily life.' 35.3% were 'able to cope with a range of printed materials but not able to use all materials encountered in daily life proficiently. 15.5% have 'good literacy skills – able to match and integrate information and perform arithmetic operations.' Finally 2.0% have 'very good literacy skills – able to use complex displays of information, use conditional information and perform multiple operations sequentially.'¹⁵

Today, patient misunderstanding is still an issue that seriously affects all forms of patient care from medication administration, wound care, presenting at the right time and place for treatment, to participation in disease prevention initiatives such as diet control for diabetes management and other more complex disease management strategies and treatment regimens. The ability to appropriately inform a patient requires the physician to be proficient in responding to the communication style and needs of diverse patient populations.

The interpersonal dynamics of non verbal communication have a significant bearing on the actual relationship between a patient and physician. Importantly, the quality of the physician's non verbal communication emits emotional cues to the patient that have the power to either enhance or inhibit the ease with which patients can share information or ask questions. Desmond and Copeland illustrate how inconsistencies in verbal and non verbal communication can create a powerful source of dissonance for the patient, severely affecting their perception of the physician's interest in their wellbeing.¹⁶ This summary is attributed to the work of Albert Mehrabian, 1972:

As much as 55 percent of the message communicated to the patient regarding his [sic] attitude and feelings is carried in his body language. The actual words he uses weigh in at only 7 percent. Another

38 percent of his attitude is conveyed by his tone of voice. Since he uses a flat, monotone voice to say, "Nice to meet you," 93 percent of the message transmitted to the patient is more like, "You're just another faceless medical case to me."¹⁷

In Desmond and Copeland's example, the quality and tone of inter-relational communication between a patient and physician, is largely determined by the professional style of the physician. The physician's ability to relate to patients and encourage information sharing is of central importance in patient centred care and in supporting patients through shared decision making. This is increasingly important where patients need additional support to understand the personal implications of medical information that is given to them in the course of their treatment.

This article is continued in Part II of Beyond Informed Consent.

ENDNOTES

¹ Hordern A, Deputy Director, Cancer Information and Support Service, *The Cancer Council, Victoria, Personal Communication*, 2007.

² National Breast Cancer Centre and National Cancer Control Initiative, 'Executive Summary' *Clinical practice guidelines for the psychosocial care of adults with Cancer*. National Breast Cancer Centre, NSW, 2003, 11.

³ Ibid.

⁴ Hordern A, *The Cancer Council, Victoria, Personal Communication*, 2007.

⁵ Fiscella K et al, 'Patient Trust: Is It Related to Patient-Centred Behaviour of Primary Care Physicians?' *Medical Care*, 42(11),

2004, 1050.

⁶ Schofield W N, et al, 'Cancellation of operations on the day of intended surgery at a major Australian referral Hospital' *Medical Journal of Australia*, 182/12, 2005, 613.

⁷ Ibid, 613.

⁸ Lobb E et al, 'Communicating prognosis in early breast cancer: do women understand the language used?' *Medical Journal of Australia*, 171, 1999, 293.

⁹ University of California, San Francisco, 'Improving Doctor-patient Communication Yields Significant Health Benefits' *Science Daily*, 2007, 1st html page, accessed at <http://www.sciencedaily.com/releases/2007/09/070928092206.htm>

¹⁰ Borosak M, 'Warfarin: balancing the benefits and harms' *Australian Prescriber*, 27, 2004, 89.

¹¹ Ibid, 88.

¹² University of California, San Francisco, 'Improving Doctor-patient Communication Yields Significant Health Benefits' *Science Daily*, 2007, 1st html page.

¹³ National Health and Medical Research Council (NHMRC) *How to prepare and present evidence-based information for consumers of health services: A Literature Review*, 2000, Commonwealth of Australia, 12

¹⁴ Australian Bureau of Statistics, '12.36 - Persons Who Speak A Language Other Than English At Home, By proficiency in English - 2001' *1301.0 - Year Book Australia*, Commonwealth of Australia, 2007, 2.

¹⁵ NHMRC *How to prepare*, 2000, Commonwealth of Australia, 12.

¹⁶ Desmond J, Copeland L, 'Chapter 4 Louder Than Words: What Your Body Language Says to Patients' *Communicating With Today's Patient, Essentials to Save Time, Decrease Risk, and Increase Patient Compliance*, San Francisco, Jossey Bass, 2000, 72.

¹⁷ Ibid.

Kate Jones



Beyond Informed Consent – Part II

Patients need both time and support if they are to participate in a model of shared medical decision making with their physicians. This paper explores the implications of patient centred care, identifies a significant barrier to patient participation in decision making, and suggests recommendations for an ethical approach to the provision of decision making support.

Patient centred care

In the context of medical care certainly not all medical decisions, despite the intention, could be said to have a therapeutic outcome for patients. This is not due to fault, or negligence, or even poor decision making. More often, it is related to the complexity of factors not within the scope of control of either the physician or patient. In diseases where the risk and onerous nature of the proposed therapy is high but the risk of not undergoing the therapy could be rapid deterioration to death, this can make decision making difficult and uncomfortable. It is in such cases that it is very important for patients to be legitimate partners with the physician in making the medical decisions that will govern permanent outcomes for life or death.

Consider for example the case of a patient residing in Darwin who urgently requires a lung transplant. Such intervention would necessitate this patient relocate to Melbourne within 2 hours travel from the Alfred Hospital's lung transplant program, to wait for a lung to become available. With limited options available for treatment for a potentially terminal condition, a decision to relocate to Melbourne or to stay in Darwin could be equally appropriate. As this program includes thorough counselling to help patients work through this difficult decision, the example is simply to illustrate the weight of consequences which make a shared model of medical decision making essential. The outcome may include a successful lung transplant in time, with a good recovery, but equally the continued deterioration of the patient without a transplant may also eventuate. There is then the heart-

ache of irreplaceable time with family and friends and the familiarity of home.

Even in cases of lesser urgency and chronicity, shared decision making between physician and patient is considered to be a popular model for making medical decisions. It affords patients greater involvement in working to match treatment options with personal values than is possible with medical paternalism, and does not leave the patient with the sole burden of making an informed choice with minimal support or guidance, as is the case with high levels of autonomy.¹ Gravel et al describe the tenets of the shared decision making model, noting that it involves:

...establishing a context in which patients' views about treatment options are valued and deemed necessary, transferring technical information, making sure patients understand this information, helping patients base their preference on the best evidence; eliciting patients' preferences, sharing treatment recommendations, and making explicit the component of uncertainty in the clinical decision making process.²

Where the physician and patient partner in a process of mutual information sharing, many dynamics affect the integrity of this process. The physician's responsiveness to the patient's concerns in the clinical process is an important factor. Research across Australia shows variable performance by doctors in this regard in different areas of patient care. In one study, Butow et al found that oncologists performed quite poorly in responding to the emotional needs elicited by patients in consultations.³ From a sample of 298 Cancer out-patients, only 28% of doctors' responses to patients seeking emotional support were appropriate. The same study found doctors were much more responsive to a patient's need for information.⁴

A patient centred approach to medical care also introduces significant responsibility for patients, but is coupled with significant benefits to the overall quality of care experienced. Gattellari et al discuss that patients who demonstrate an active interest in information and ask questions are more likely to be provided with the medical information they desire.⁵ Simultaneously, a patient's active participation in the management of their illness can be empowering in a number of areas. Knowing what to expect can alleviate the anxiety associated with uncertainty, and assists patients to be adequately prepared for their experience. A more detailed understanding of the disease process better equips patients to engage in the safety surveillance of their own condition and physiological idiosyncrasies. This may be important in expedient assistance with medical complications and adverse effects. Importantly, it better enables patients to engage a role of authority in negotiating and consenting to the choices that shape their own clinical pathway. This all

serves to give patients a greater sense of control where it is wanted.

A patient centred approach to care requires practitioners to be flexible in their partnership approach with patients. A patient's preference for involvement may move between a reluctance to participate in a complex medical decision, to a desire to share decision making with physicians, to the other extreme where patients wish to maintain a high degree of autonomy in medical decisions that affect them.⁶ It is also essential to consider that participation in decision making will mean different things to different patients. The characteristics that give meaning and value to the working partnership between patient and physician are highly personal and variable. It is also not necessarily just the right to select a particular choice that leads to a patient feeling that they have reached their desired level of participation.⁷ The National Breast Cancer Centre suggests 'Ensuring that patients feel involved in decision-making may be more dependent on the communication skills of the clinician than on the provision of treatment choices.'⁸ Medical consultations that foster mutuality, trust and a sense of connectedness between patient and physician may be integral to the patient's belief that their involvement is valuable. Henman et al comment on the dynamics that substantiate this: 'These women found involvement in decision making to be critical to their sense of self respect and coping, rather than feeling that the right decision could only be made with their input. As with information, involvement did not necessarily mean they wanted to take responsibility for the decision.'⁹ Besides exhibiting varying capabilities to manage complex information, it stands to reason that patients will be influenced by unique personal agendas that determine their actual level of participation in the management of their condition.

Barriers to patient participation

A significant problem experienced by patients with chronic illness is a lack of psychosocial support services. Not only does this have the potential to reduce self efficacy and a sense of coping in a range of areas, but it may also limit a patient's ability to participate in medical and personal decision making. This is a particular problem in Victoria and across Australia for people with cancer. It has been suggested that it is an area of unmet need that is even more of a problem for patients whose chronic illness is not cancer related, or is non-malignant.¹⁰ For people already suffering the effects of social isolation caused by chronic illness, the absence of professional support to cope with the emotional demands of illness can be particularly damaging.

The absence, or at best inadequacy, of psychosocial support services for people with cancer is widely expressed from within the acute health sector in Melbourne. Dr Braithwaite from Caritas Christi, St Vincent's Health,

Melbourne, discussed 'Poor access to dedicated psychology services where they are needed for patients is a real challenge for clinicians who identify the need. It is also particularly devastating for hospital patients who desperately require psychological or psychiatric treatment but for whom the support is not available.'¹¹ The Monash Medical Centre submission to the Senate Inquiry into gynaecological cancer services in Australia stated in 2006: 'Many of our patients are under considerable psychological stress at the time of admission to our unit...and we have no professional support to offer them at this time or in the following period...This situation is not unique to our Unit and is standard in most Units around the country...'¹² In response to the same submission a Gynaecological Oncologist from Melbourne stated: '...Addressing the needs of women has been inadequate. Very few of the gynaecological cancer units in Australia have clinical psychologists to address these needs. A clinical psychologist with expertise should be funded for all units.'¹³

In the metropolitan hospital system in Victoria, it can be extremely difficult to access professional psychological support for a patient. The exception to this is usually a level of extreme distress where for example, a patient is considered to be suicidal.¹⁴ Whilst in Victoria the Cancer Council makes a significant impact for patients in filling this service gap in the community, patients suffering in the acute setting in hospital may be particularly vulnerable.

Ethical approaches to enhancing patient participation

Some of the reasons contributing to a lack of psychosocial support for chronically ill people are complex, but remedies to alleviate the demand for such support could be addressed with only minor changes to practice. This is particularly true where patients do not have severe or ongoing psychiatric health problems.

Of particular interest is the finding highlighted by Schofield et al that the support of significant others, that is, people already in a meaningful professional or personal relationship with the patient, may be particularly effective in buffering the emotional difficulties of anxiety and distress.¹⁵ Insight into the relational needs of people, embedded within the make up of humanity, informs this finding. Universally, supportive relationships out of which personal concerns and fears can be discussed, practical help provided, and encouragement given at a time of despair, are therapeutic. Schofield et al comment on a systematic review conducted by Newell et al in 2002:

In a recent systematic review of 329 trials of psychological interventions for cancer patients, it was concluded that group based therapies require further research before recommendations can be made

about their use to reduce anxiety and depression, improve general affect and coping and increase survival time. Informational and educational interventions also warrant further research...The involvement of significant others in psychosocial interventions for cancer patients reduces their anxiety and distress and enhances their QoL.¹⁶

Based on a synthesis of the current research literature and on the finding that the involvement of significant others is a particularly helpful aspect of psychological support, this paper will close with two recommendations to enhance patient participation in their desired level of decision making.

Recommendation one: In addition to recognising the important dynamics of quality communication, physicians need to establish a reliable referral network of trusted professional connections, so that patients who are found to be distressed, disturbed or not coping can receive the psychosocial attention they deserve. Such connections may include pastoral care workers, social workers, psychologists and psychiatrists, practitioners of safe alternative therapies, as well as a variety of other support workers particularly known to specific communities. Butow et al confirm that because patients may not articulate a need for emotional support, even when the need for it is high, physicians should not wait for patients to ask for such assistance.¹⁷ Steginga et al similarly report 'First clinicians tend to overlook patients' psychosocial needs, such that many distressed patients remain unidentified... Second, patients' desire for support has been found to not correlate to their levels of psychological distress.'¹⁸

The communication patterns used by physicians, establishes an important precedence in the patient's quality of care. Research evidence from Australia and overseas suggests that patients generally need a supportive environment to integrate and make personal sense of complex medical information. The physician's improved relational interaction with patients involves not only an openness to the clues in each patient's verbal and non verbal communication, but also a certain generosity of spirit, or willingness to give the patient personal, as well as professional, presence. The balanced provision of appropriate personal presence, support to make decisions, useful information, and clinical management is a delicate one. But a lot of weight can be given to Stewart's reflection 'Sometimes, our difficulty is a failure to understand that what the patient wants is something very simple: a recognition of his or her suffering or perhaps only our presence at a time of need.'¹⁹

Recommendation two: Consideration across Australia needs to be given to the benefits of establishing a tiered model of access to psychosocial support for people with cancer and other chronic illnesses. One such model, the Queensland Cancer Fund tiered model, has already been

presented by Steginga et al, in *Cancer Forum*, a publication of the Cancer Council of Australia.²⁰ The model streamlines five different levels of therapeutic intervention where resources are allocated increasingly to match increasing intensity of need, characteristic of a stepped care approach. This model has two particular features that contribute to its effectiveness. Steginga et al clarify it has a triage system to guide a patient's access to the appropriate level of service intervention and is accompanied by a training package for staff.²¹

Such a model is desirable in Victoria and other locations around Australia because it may more efficiently target psychosocial resources where they are most needed. This is particularly appropriate in the current environment where significant budgetary constraints limit the availability of such services. From a resource perspective, the model acknowledges the impossibility of providing intense psychosocial support services to every patient. Such a model is consistent with the conventional wisdom that a response that is both integrated and multidisciplinary is needed to meet the current level of unmet psychosocial service demand across the acute, sub acute and community sectors.

Conclusion

In complex medical matters, attention to a patient's need for support is worthy of considerable attention. It might be a need for assistance to understand information, or assistance to work through emotional issues that equally impact decision making ability. That the need for such support is not immediately obvious does not lessen the physician's responsibility in this regard. An important work of the physician is to understand the illness in the context of the patient's life, where matters of importance are moulded into schemes of personal preference and familiar value systems. An appreciation of what matters to patients enriches the dialogue between patient and physician, which can positively contribute to a patient's sense of wellbeing, even in deteriorating health.²²

ENDNOTES

¹ Henman M.J et al, 'Lay Constructions of Decision-Making in Cancer' *Psycho-Oncology*, 11, 2002, 295,296.

² Gravel K et al, 'Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review

of health professionals' perceptions' *Implementation Science*, 1/16, 2006, 2.

³ Butow P.N et al, 'Oncologists' Reactions to Cancer Patients' Verbal Cues' *Psycho-Oncology*, 11, 2002, 53.

⁴ Ibid.

⁵ Gattellari M et al, 'When the Treatment Goal is Not Cure: Are Cancer Patients Equipped to Make Informed Decisions?' *Journal of Clinical Oncology*, 20/2, 2002, 510.

⁶ Lambert S.D, Loiselle C.G, 'Health Information-Seeking Behaviour' *Qualitative Health Research*, 17/8, 2007, 1009.

⁷ National Breast Cancer Centre and National Cancer Control Initiative' *Clinical practice guidelines for the psychosocial care of adults with cancer*, National Breast Cancer Centre, 2003, NSW, 61.

⁸ Ibid.

⁹ Henman M, 'Lay Constructions of Decision-Making In Cancer' *Psycho-Oncology*, 11, 2002, 300.

¹⁰ Dr Braithewaite M, Head, Clinical Psychology, Caritas Christi Hospice, St Vincents Health, Melbourne, *Personal Communication*, 2007.

¹¹ Ibid.

¹² Monash Medical Centre – Gynaecological Oncology Unit, Submission to the Senate Community Affairs Committee, Parliament of Australia, *Inquiry into Gynaecological cancer in Australia*, Melbourne, 2006, 5.

¹³ Associate Professor Rome R, Associate Director Oncology and Dysplasia Unit, Royal Women's Hospital, Melbourne, Consultant in Gynaecological Oncology, Submission to the Senate Community Affairs Committee, Parliament of Australia, *Inquiry into Gynaecological cancer in Australia*, Melbourne, 2006, 1.

¹⁴ Dr Braithewaite M, *Personal Communication*, 2007.

¹⁵ Schofield P, Carey M, Aranda S, 'Psychosocial Issues for People With Advanced Cancer: Overcoming The Research Challenges' *Cancer Forum*, 30/1, 2006, 19.

¹⁶ Ibid.

¹⁷ Butow P.N et al, 'Oncologists' Reactions to Cancer Patients' 11, 2002, 48.

¹⁸ Steginga S.K et al, 'Translating Psychosocial Care: Guidelines Into Action' *Cancer Forum*, 30/1, 2006, 29.

¹⁹ Stewart M et al, 'Chapter 7 The Fifth Component: Enhancing the Patient-Doctor Relationship' in Stewart M et al *Patient-Centred Medicine*, Transforming the Clinical Method, London, Sage Publications, 1995, 93,94.

²⁰ Steginga S.K et al, 'Translating Psychosocial Care: Guidelines Into Action' 30/1, 2006, 29, 30.

²¹ Ibid.

²² If you have a question about cancer, Call the Cancer Council Helpline on 13 11 20, Monday to Friday from 8.30 – 8.00pm. All calls are confidential and interpreters are available.

Kate Jones



NHMRC Statements on Post-Coma Unresponsiveness

This article reviews three statements from the National Health and Medical Research Council on post-coma unresponsiveness (PCU).

One of the functions of the National Health and Medical Research Council (NHMRC) is to propose standards and guidelines for health care in Australia. In this capacity, it has recently considered the condition of PCU. To date, it has produced three statements on this issue. These are ex-

amined below:

2004 Information Paper

In 2004, the NHMRC released *Post-Coma Unresponsive-*

ness (*Vegetative State*): *A Clinical Framework for Diagnosis*.¹ As the title implies, its focus is the diagnosis of this condition. It was released only as an information paper because it was “not possible to gather a level of evidence... adequate to justify clinical guideline recommendations.” (p. 2, cf 42)

PCU was originally called persistent or permanent vegetative state. This statement notes several reasons to reject these terms. The word ‘vegetative’ is “potentially pejorative if misunderstood by families or carers as being synonymous with vegetable.” Further, to call this condition ‘persistent’ or ‘permanent’ “may lead to withholding of opportunities for rehabilitation or limitation of access to other treatments.” (p. 51) Instead, this report refers to ‘post-coma unresponsiveness (VS),’ which includes the abbreviation of the older term as a reminder that the two terms are synonymous. (p. vi)

PCU occurs when a patient emerges from a coma into “an apparently wakeful unconscious state in which there is:

- a complete lack of responses that suggest a cognitive component;
- preservation of sleep-wake cycles and cardiopulmonary function; and
- partial or complete preservation of hypothalamic and brain-stem autonomic functions.” (p. ix, cf v, 6, 43-46)

Because of the great difficulties in diagnosing PCU in infants under one, the report restricts this condition to those beyond this age. The diagnosis should first be considered “approximately four weeks after the appearance of unresponsive wakefulness. Regular reassessment is required.” (p. ix)

Most of the content of this report is collected in six chapters. The first of these is a literature review. This explores all peer-reviewed studies published in English before July 2001, additional papers published after that date, and guidelines from various medical organisations. These are listed at the end of the report. (p. 57-62) Most papers, however, are simply case studies, which provide only limited information. The chapter concludes by offering suggestions for future research. Above all, it proposes the establishment in Australia of a nationally coordinated coma register. (p. 5, cf viii, 20)

The second chapter explores the causes and neuropathology of PCU. Its causes are usually mechanical trauma (eg a car accident) or hypoxia (eg lack of oxygen to the brain after an operation). There is usually “extensive damage in the thalami, the cerebral cortex and the white matter of the cerebral hemispheres, in various combinations.” (p. 11) However, other patients suffer very similar damage without becoming unresponsive.

Chapter Three details differential diagnosis from similar conditions, including brain death, coma, locked-in state,

minimally responsive state (MRS), severe brain damage, and akinetic mutism. While the minimally responsive state involves profound cognitive impairment, it nonetheless manifests “minimal but definite evidence of awareness.” (p. 16, cf 15) In practice, MRS is particularly difficult to distinguish from PCU. (For example, on page 19, the report cites one study in which 43 percent of a cohort of 40 were incorrectly diagnosed by specialist practitioners.)

Chapter Four discusses diagnosis of PCU. Such diagnosis is “an iterative process that should occur over a long period of time,” (p. v) with reassessments “initially... carried out at least every four weeks.” (p. ix) Because of the difficulties of diagnosis, medical practitioners without personal experience of the condition should consult with an experienced practitioner. (p. 20) The patient’s family and carers should be involved in assessment “as it is unlikely that patients in a totally dependent condition will otherwise be sufficiently reassured and able to provide a reliable indication of their capacity to respond.” (p. x) The report emphasises that during this time there must be clinical management “to maintain the optimal clinical state of the patient, prevent secondary complications and obviate suffering and discomfort. Such measures may include artificial nutrition and hydration, pressure care, range of movement exercises, and bowel and bladder care.” (p. 21)

The fifth chapter considers imaging and other tests. These tests could exclude remediable disease processes such as a lesion. They could also demonstrate “irreversible structural brain damage or absence of normal cerebral function.” (p. xi, 25) However, “awareness cannot be reliably excluded by any of these tests,” and “no ‘gold standard’ test is available or imminent.” (p. xi) For this reason, “the NHMRC considers that post-coma unresponsiveness (VS) must be diagnosed primarily through clinical examination.” (p. 25)

Chapter Six explores prognosis, particularly emergence from unresponsiveness. It cautions that emergence rarely means full recovery: usually, there is “substantial residual disability.” Any improvement may be “both gradual and prolonged.” Factors that influence outcome are “the cause, extent and type of brain injury, the length of time that the person has been unresponsive, and his or her age.” (p. 33-34) Prognosis is better after trauma than after hypoxia. The report does cite studies with figures like 13, 20, 26, 33 and even 58 per cent emerging from unresponsiveness. However, there are limitations to all these studies, and the report concludes that it is not possible even “to make a reliable estimate” of the percentage of patients who emerge.

Finally, note that this 2004 statement does offer brief comments about the care of patients with PCU. They are “a subset of patients with severe brain injury.” (p. 38)

Therefore, the ethics of their management are “the same as the ethics of managing any other highly dependent person.” (p. v)

2007 Draft Documents

A subsequent document from the NHMRC explores care in more detail. Issued in 2007, this is *Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State*.² It was released along with *Post-Coma Unresponsiveness and Minimally Responsive State: A Guide for Families and Carers of People with Profound Brain Damage*.³ Both are draft documents. Especially because of the difficulties of differential diagnosis, both consider both PCU and MRS.

Most of the content of the first of these draft documents is collected in seven chapters. The first three of these are titled Introduction, PCU and MRS in Australia, and Diagnosis and Prognosis. In the main, these review information we have already discussed. After these sorts of brain injury, “most recovery of useable function occurs in the first two years.” (p. 7)

Chapter Four discusses the Goals and Components of Care. The goals are to care for both the affected person and his/her family. For the affected person, this entails supporting him/her physically, socially, emotionally and spiritually, maximising any recovery, preventing deterioration, and relieving possible pain or discomfort. “Without adequate medical and physiotherapy care, a person in PCU or MRS may become moribund and develop contractures that compromise care and lead to life-limiting conditions such as respiratory failure.” (p. 10)

Chapter Five considers Responsibility and Process for Decision-Making. It reviews advance care planning, advance care directives, and the appointment and role of a patient representative. Because decisions must be made in the person’s best interests, there is an account of relevant considerations for this determination. Legal advice should be sought if a binding advance directive does not seem in the patient’s best interests.

The sixth chapter is on Communication, Teamwork and Support. It notes that “optimal care... is achieved through teamwork... in partnership with the family. Good, two-way communication... is fundamental to this.” (p. 15) The chapter then provides many guidelines on effective communication. Because “it is not possible to be certain that a person in PCU or MRS is unaware,” all dealings with them “should be conducted on the basis that they may be aware” (p. 15) The document emphasises “early, open and ongoing communication” with the family, “including acknowledgement of uncertainties in diagnosis and prognosis.” (p. 16) Realistically, it notes that families may suffer financial hardship, and health professionals

may be at risk of burnout. Various forms of support are needed to remedy this.

The seventh chapter is on Sites and Levels of Care. Above all, this chapter continues the discussion about determining a patient’s best interests. It considers futile and overly burdensome treatments - which ethically may be refused. (Curiously, the guidelines never exactly say this.) Treatment is overly burdensome “when the burden of treatment... is disproportionate to the likely benefits.” Treatment is futile “only if it produces no benefit to the patient,” where such benefits include “slowing down the progress of disease,” “sustaining the person’s life,” “reducing disability and improving health,” and “relieving the person’s distress or discomfort.” (p. 28) The guidelines recommend “discussion.... between health care staff and family of whether resuscitation is to be attempted in the event of respiratory or cardiac arrest.” (p. 29) They also discuss maintenance care, which includes artificial nutrition and hydration. Except when there are complications, the guidelines hold that “the presumption ought to be in favour of continuing maintenance care.” (p. 29)

Finally, the guidelines again call for the “establishment of a nationally coordinated coma register, which could be extended to include related conditions such as PCU and MRS.” (p. 32)

The second draft document is a guide for families and carers. It covers many of the topics from the guidelines in simpler language. It also includes other useful information, such as what financial or other help might be available from various government agencies, or where to seek advice about the appointment of a patient representative. A pleasing feature is the use of stories and quotes to give the discussion a human face.

I gave a copy of this guide to a family with a member who is arguably in PCU. They were at first hesitant. Would it be too complicated for them to understand? Would it say anything useful? Eventually, however, they downloaded and printed extra copies, and gave one to every member of the family. This is eloquent testimony to the value of this resource.

Critical Comments

I conclude this review with two critical comments:

Firstly, the statements note correctly that family are often the first to notice subtle changes in the patient, including the beginnings of purposeful and responsive activity. However, I believe that they should state more explicitly that family reports may also be seriously incorrect. Let the case of Terri Schiavo serve as an example. After a cardiac arrest on 25 February 1990, Schiavo suffered severe brain damage due to a lack of oxygen. Almost cer-

tainly, she remained in a state of PCU for the next fifteen years, until her death on 31 March 2005. Just before her death, however, her family of origin claimed that she had tried to say, "I want to live." Indeed, they argued that she was often talkative. While words were usually not discernable, they claimed that her voice changed to express emotion. They also said that she was responsive to commands. Nothing is impossible, but these claims are almost certainly incorrect. When a family sits for so long with someone they love, they want desperately to see some response. Sometimes, through wish fulfilment or self-deception, they see something that really is not there. In my opinion, the NHMRC statements need to be more explicit about this possibility, and also offer advice to health professionals about what to do in these circumstances.

Secondly, the 2007 documents in particular need to be more explicit about whether or not in the absence of complications it is ever appropriate to withhold or withdraw artificial nutrition and hydration (ANH) from a PCU patient. The implication of the documents is that this is not appropriate. Others might hold that a treatment is futile if it does not restore a person to a state where they can "strive for the spiritual purpose of life" by loving God, self, and neighbour.⁴ However, these statements hold that treatment is not futile if it simply sustains a person's life in PCU. Does the NHMRC - like official Catholic teaching⁵ - hold that in the absence of serious complications it is always wrong to withhold or withdraw ANH from PCU patients? While that is the implication, this is never stated explicitly.

In my opinion, this is a serious weakness in the statements. Part of the tragedy of the Schiavo case was the conflict between family members about what was truly in her best interests. On one side, her ex-husband Michael believed that it was in her best interests to withdraw ANH and let her die. On the other side, her family of origin believed it was in her best interests to continue ANH and let her live. Especially when a person remains in PCU for

many years, other families will face similar conflicts. Some patient representatives will face this same conflict within themselves. All these people deserve better and clearer guidance on this issue from the NHMRC. And if there is genuine division within the NHMRC about withholding or withdrawing ANH from PCU patients, it is both more honest and more helpful to admit that too.

ENDNOTES

¹ This document can be accessed online at http://www.nhmrc.gov.au/publications/synopses/_files/hpr23.pdf As noted on pages 47 and 50, there were two public consultations as part of the process of preparing this paper. This Centre made a submission to both those consultations.

² This document can be accessed online at http://www.nhmrc.gov.au/consult/_files/PCU_health_professionals_consultation_draft.pdf The process of preparing this document began with a targeted consultation to which this Centre made a submission.

³ This document can be accessed online at http://www.nhmrc.gov.au/consult/_files/PCU_consumer_guide_consultation_draft.pdf There was public consultation after these two draft documents were released. Again, this Centre made a submission.

⁴ Benedict M. Ashley and Kevin D. O'Rourke, *Healthcare Ethics: A Theological Analysis* Third Edition (St Louis: Catholic Health Association of the United States, 1989), 381.

⁵ John Paul II, "Address to Participants in the International Congress on 'Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,'" http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html; Bishops Commission for Doctrine and Morals, Australian Catholic Bishops Conference, "Briefing Note on the Obligation to Provide Nutrition and Hydration," <http://www.acbc.catholic.org.au/bc/docmoral/2004090316.htm>; Congregation for the Doctrine of the Faith, "Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration," http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html

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