PATIENT ADVOCACY AND ADVANCE CARE PLANNING IN THE ACUTE HOSPITAL SETTING

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In memory of a voiceless patient whose silent suffering caused me to grieve deeply that we as a culture could not step back from our striving to see how we had violated trust by not allowing him to pass away with even a shred of human dignity left.

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Key words: patient advocacy, ethics, advance care planning, hospitals, advance directives, nurses.

ABSTRACT

Objective:

The aim of this study was to explain the role of patient advocacy in the Advance Care Planning (ACP-ing) process. Nurses rate prolonging the dying process with inappropriate measures as their most disturbing ethical issue and protecting patients' rights to be of great concern (Johnston et al 2002). Paradoxically ethical codes assume nurses have the autonomy to uphold patients' health-care choices. Advance Directives (AD) designed to improve end-of-life care are poorly taken up and acute hospitals are generally not geared for the few they receive. The Respecting Patient Choices Program (RPCP) improves AD utilisation through providing a supportive framework for ACP-ing and primarily equipping nurses as RPC consultants. Assisting patients with this process requires attributes consistent with patient advocacy arising out of nursing's most basic tenet, the care of others.

Design:

Likert Scales survey administered pre and six months post-intervention to pilot and control groups, with coinciding focus groups.

Setting:

Selected wards in an acute care public hospital in South Australia.

Subjects:

Nurses on the palliative care, respiratory, renal and colo-rectal pilot wards and the haem-oncology, coronary care, cardiology and neurology/geriatric control wards.

Intervention:

The RPCP during the 2004-2005 South Australian pilot of the (RPCP).

Main outcomes:

The organisational endorsement of ACP-ing gave nurses the autonomy to be patient advocates with respect to end-of-life care, reconciling clinical practice to their code of ethics and easing distress about prolonging the dying process inappropriately.

Results:

Statistically significant survey results in the post-intervention group showed nurses experienced: encouragement to ensure patients could make informed choices about their end-of-life treatment (84%); the ability to uphold these wishes in practice (73%); and job satisfaction from delivering appropriate end-of-life care (67%); compared to approximately half (42-55%) of respondents in the pre-intervention and control groups. Focus group participants shared that it used to be hard to advocate for patients, but now they could act legitimately and felt ethically comfortable about ensuing end-of-life-care.

Conclusion:

Findings suggested patient advocacy, fostered by the supportive RPC environment, effectuates the ACP-ing process. It is recommended that the RPCP should be recognised and developed as integral to promoting quality end-of-life assurance and associated job satisfaction.

INTRODUCTION

The aim of this study was to explain the role of patient advocacy in the ACP-ing process. An advance care plan (ACP) is documentation that makes a person's wishes known about possible future medical treatment in the event of loosing capacity to communicate (OPA 1999). Assisting patients with the ACP-ing process involves ensuring they understand life prolonging treatment options; their legislative rights to ADs; and, in consultation with their loved ones and health care providers, to document and communicate their end-of-life care treatment preferences (Austin Health 2004). Facilitating this process requires a willingness to establish a therapeutic relationship with the vulnerable patient; enable the patient to be involved in decision-making; and serve as a mediator between the patient and other parties. These attributes, according to Baldwin's (2003) concept analysis, represent the presence of patient advocacy.

The investigator for this research, a registered nurse at a major teaching hospital's Division of Critical Care speciality pool, helped implement the RPCP at the hospital and job-shared the RPC Project Officer position. The program was launched in October 2004 as part of the National Palliative Care Program's RPCP pilot extension to a lead hospital in each State and Territory of Australia following Austin Health's successful trial in Melbourne, Victoria, Australia. This research project contributed toward a current masters undertaking in Health Science (Health Promotion) through Deakin University Melbourne.

BACKGROUND

In the acute care hospital setting, should the patient lose competence in the absence of AD or medical instructions to the contrary, life sustaining measures including cardiopulmonary resuscitation (CPR) are routinely implemented. For nurses who do not have authority to make decisions on these matters, the position can be particularly distressing if the patient is terminally ill, very frail and elderly or has expressed the wish to avoid such measures (Johnson 2004; Taylor and Cameron 2002). Furthermore, provision for people to exercise self-determination at end-of-life through the use of AD is poorly taken-up with only a 12.5 % prevalence in the South Australian (SA) community in 2004, translating to 1% of hospital case-notes containing advance directives in that same year (DHS 1999; Harrison Health Research 2004; Foote 2004).

In addition, health professionals are often unfamiliar with ADs and hospitals are generally not geared for the few they receive (Austin 2004). These issues are reflected in Johnson et al's (2002) Final Report to the Nurses Board of Victoria, *Registered nurses' experiences of ethical issues in nursing practice*, which lists 'prolonging the dying process with inappropriate measures' as the registered nurse's 'most disturbing ethical/human rights issue' (p.31) and 'protecting patients' rights and human dignity (p.7) to be of great concern.

Issues contributing to these matters include the perceived complexity of completing AD documents, directives being unavailable when needed, and incomplete or ambiguous directives (Brown et al 2005; Austin 2004). Health professionals may resist end-of-life discussions for fear of upsetting the patient, although studies show such discussions improve patients' perception of care (Steinberg et al 1996; Austin 2004). Nurses are more likely to initiate conversations if they feel they have the necessary skills and if they have previously cared for a patient with an AD (Lipson et al 2004).

Johnson (2002; 2004) suggests that because nurses have the opportunity to be in communication with their patients, they be empowered as patient advocates and Pincombe et al (2004) after observing patients dying in South Australian public hospitals recommended developing patient advocacy to ensure care better reflected patient and family needs. However patient advocacy can be risky; nurses have stood to lose their jobs following advocacy efforts due to a lack of a support structure for the process (Baldwin 2003; ABC 2005). In addition, simply giving permission for nurses to talk with patients does not endow the advocacy skills needed to facilitate ACP-ing (Briggs 2004).

A collaborative hospital and community program that does equip nurses to assist patients with ACP-ing called RPC was successfully piloted in Australia by Austin Health, Melbourne, Victoria, Australia in 2002-2003. Originally developed at the Gunderson Lutheran Medical Centre, Wisconsin, (United States of America) the program (which does not support euthanasia or suicide) focuses on the quality of the ACP-ing process; ensures copies of the patient's document are placed in an easily accessed green-sleeve at the front of current case notes; and requires all staff involved in the care of patients to be educated about the implications of AD in everyday practice (Hammes and Rooney 1998; Austin Health 2004). Heland (2003), the original RPC Project Officer at Austin Health noted 'the nurse was empowered' by the program and 'given the opportunity to really care again' (p.1).

Care of others is nursing's most basic tenet, in which patient advocacy is ethically grounded. It pertains to fostering and protecting in order to promote well-being whether in a return to health or facilitating a peaceful death. Counselling to ensure patients can make educated decisions about their health care needs and protecting and supporting their rights describes the act of patient advocacy (Baldwin 2003; Taylor et al 1993). The *Code of Ethics for Nurses in Australia* (ANC 2002) pledges to 'accept the rights of individuals to make informed choices in relation to their health care' (p.3) and 'uphold these rights in practice' (p.1). However the code is at odds with the discipline as revealed by the report to the Nurses Board of Victoria: such codes assume nurses have the autonomy to empower patients (Baldwin 2003).

It follows that effective patient advocacy not only depends on the attributes and skills of the advocate, but also on the perceived receptiveness of the organisational environment, which may prompt or repress the act, as well as the actual responsiveness of the environment, which may determine its outcome.

It was hypothesised that patient advocacy, fostered by the framework and tools the RPCP program provides, effectuates the ACP-ing process, promoting quality end-of-life assurance and associated job satisfaction; where the intervention variable, the RPCP, provides a framework of educative, patient information, safety and quality systems and policy support for ACP-ing, along with equipping mainly nurses, through a comprehensive two day training course, with skills and resources to facilitate the process.

The outcome variables are described as:

1. `Fostered patient advocacy', which denotes an environment that is encouraging of the act of patient advocacy with respect to informed choice about end-of-life care;
2. `Quality end-of-life assurance', meaning the empowering process of ACP-ing eventuating in patient valued treatment in end-of-life care and a 'good death' (a 'good death' according to anthropological and historical archives includes awareness, adjustment, preparation, disengagement and time to say goodbye (Kellehear 1999); and
3. `Associated job satisfaction', which represents being able to deliver dignifying end-of-life care perceived to be both appropriate and congruent with the patient's wishes.

METHOD

A prospective non-randomised control trial was conducted using convenience sampling in the partially manipulated natural setting of hospital wards. The triangulation of quasi-experimental and semi-structured focus group methods enabled quantitative outcomes to be supplemented with qualitative information to enrich the research and enhance validity (Burns and Grove 1993; Sim and Wright 2002). Approval to conduct research was given by both the hospital and University Human Research Ethics Committees. The first phase RPC implementation wards served as the pilot group and second phase wards as the control group. The sample population of nursing staff from all levels was considered representative of the target population, nurses in other large metropolitan public hospitals, due to commonality under professional standards and industrial and employing State practice codes (Sim and Wright 2002).

A 5-point Likert scales questionnaire was developed through trialling and then administered to nurses in the pilot and control groups prior to the launch of the program and again at six months post-intervention. Ballot boxes were placed in hospital ward staff rooms for the anonymous return of questionnaires. The average sample size for each group was 139 with a questionnaire return rate of 76.5 (55%). There were 67% of the same control and 72% of the same pilot group staff present during both surveys, however questionnaires were not linked and so there will be some overlap. Of the post-test pilot group respondents, 43% had not undertaken RPC consultants training (30% unknown). Therefore the study measured the general effect of the RPCP intervention on the hospital ward nurse's perception, not just the effect on those who underwent RPC Consultancy training (table 1).

Analysis was performed separately for pilot and control groups on each question to compare pre-test with post-test responses using a Chi squared test of independence. The 'strongly agree' and 'agree' responses were combined as were the 'strongly disagree' and 'disagree' responses, to form a 3 by 2 contingency table with the neutral responses. If a cell had an expected count less than 5, to overcome potential bias, a Fisher Exact test was performed. Stacked bar charts were created to visualise the degree and direction of changes. On the questions (dependent variables) that demonstrated statistically significant changes using the Chi squared test, a multiple regression analyse was also performed to compare pre-test post-test pilot and control group data. The analysis looked at group, time, and group time interaction (predictor variables).

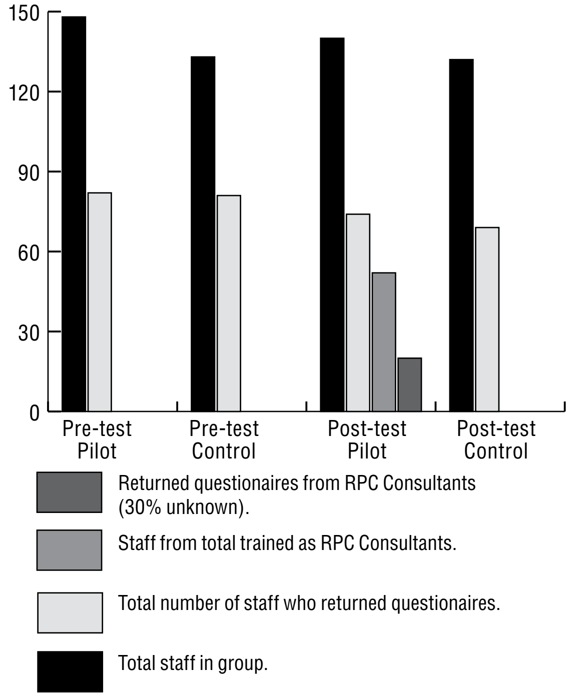
Table 1:

Sample group staff numbers and survey returns at pre-test baseline October 2004 and post test six months April/May 2005.

Pilot Group

- Renal: 28 beds, average 42 staff (RPC trained 18), returns pre-test 43%, post-test 43%
- Palliative Care: 12 beds, average 18 staff (RPC trained 9), returns pre-test 74%, post-test 82%
- Colo-Rectal: 36 beds, average 51.5 staff (RPC trained 16), returns pre-test 73%, post-test 48%
- Respiratory: 20 beds, average 30.5 staff (RPC trained 9), returns pre-test 35%, post-test 58%

Total: 96 beds, average 142 staff (RPC trained 52), returns pre-test 61%, post-test 52%



Control Group

- Haem-Oncology:16 beds,average 28.5 staff, returns pre-test 61%, post-test 50%
- Coronary Care: 10 beds, average 29 staff, returns pre-test 96%, post-test 56%
- Cardiology: 26 beds, average 34 staff, returns pre-test 57%, post-test 58%.
- Neurology/Geriatrics: 32 beds, average 41 staff, returns pre-test 42%, post-test 46%

Total: 84 beds, average 132.5 staff, returns pre-test 55%, post-test 53%

Note: *Pre-test conduction: 17-27.10.2004 shorter time period due to the launch of RPCP on 27/10/04 and Deakin Human Research Ethics approval 18.10.2004 and TQEH HREC approval on the 30.08.200. Post-test conduction: 14.04.2005-06.05.2005.

Two focus groups with voluntary participants from both pilot and control groups were conducted prior to the RPCP implementation and one with pilot group staff only at six months. Discussions were audio-taped and the transcribed data was manually cut and pasted into themes with descriptive codes. The categories were then linked to identify relationships (axial coding) and provide insight into survey responses and the participant's views about the research topic (Sim and Wright 2002; Burns and Grove1993).

QUANTITATIVE FINDINGS

In both pre and post-test pilot and control groups most nurses (77-87%) agreed that prolonging the dying process with inappropriate measures is nursing's most disturbing ethical issue; although they separated this issue from their clinical practice by disagreeing (62-70%) that they felt personal ethical conflict. Nurses also indicated (98-100%) that respect for patient self-determination at end-of-life was important and that delivering quality end-of-life care should give job satisfaction (94-96%). There was uncertainty (34-58%) about the validity of end-of-life care information in a crisis, although the post-test pilot group had the most confidence of all the groups. Likewise, trust in such information's availability in a crisis was poor in all groups (15-24%).

Up to half of the nurses (30-49%) agreed they felt powerless to advocate for their patients with respect to the appropriateness of their end-of-life care, although the pilot group nurses' agreement with the statement reduced to 19% post-intervention. Both post-test groups showed a statistically significant shift toward believing there was an end-of-life care policy in place. Awareness throughout the hospital of the RPC pilot would have contributed to this and a draft policy (Box 1) had been left on the haem-oncology control ward when an RPC proposed extension talk was given. Removing this wards post-test data reversed the result for the control.

Box 1: Core policy issued for the first time in July 2005 stated: 'TQEH is committed to respect patient's rights to self determination in their end of life care and medical treatment (Advance Care Plan) pursuant to the *Consent to Medical Treatment and Palliative Care Act 1995* and *Guardianship and Administration Act 1993* by educating staff and maintaining hospital systems that will ensure the plans are honoured.'

Outcome variable 1: fostered patient advocacy

A statistically significant change in the post-test pilot group was identified using the Chi squared test on Q.11, which did not occur in the control (pilot < 0.001, * $p < 0.05$; control 0.145). In effect, 84% of post-test pilot nurses agreed they felt encouraged in their work environment to ensure patients understood and could make informed choices about future treatment compared to an average of 49% in baseline and post-test control groups (range 42-55%) (table 2). The multiple regression also showed a statistically significant interaction effect for dependent variable Q.11, ($p = 0.042$).

Table 2:

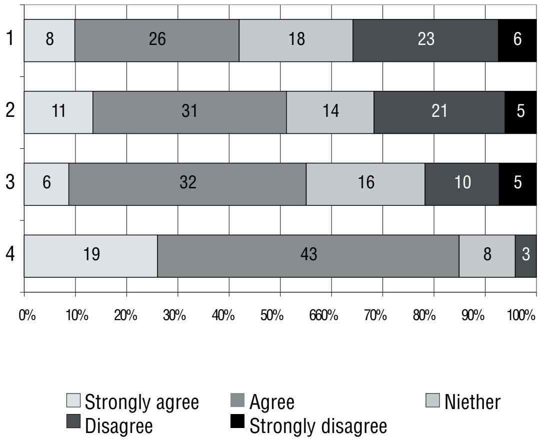
Q11: In my work environment I am encouraged to ensure patients understand and can make informed choices about their end of life treatment.

1. Pre-test Control Oct 2004 n=81

2. Pre-test Pilot Oct 2004 n=82

3. Post-test Control April 2005 n=69

4. Post-test Pilot April 2005 n=74



Outcome variable 2: Quality end-of-life assurance

Another statistically significant change was found in the post-test pilot group using the Chi squared test on Q.7, which did not occur in the control (pilot 0.016*, * $p < 0.05$; control 0.670). In effect, 73% of the post-test pilot nurses agreed they were able to uphold the end-of-life care wishes of their patients compared to 54% in the base line and post-test control groups (table 3). The combination of this outcome with outcome variables 1 and 3 represents `Quality end-of-life assurance'. The multiple regression analysis showed similar results to the Chi squared test but was not as statistically significant.

Table 3:

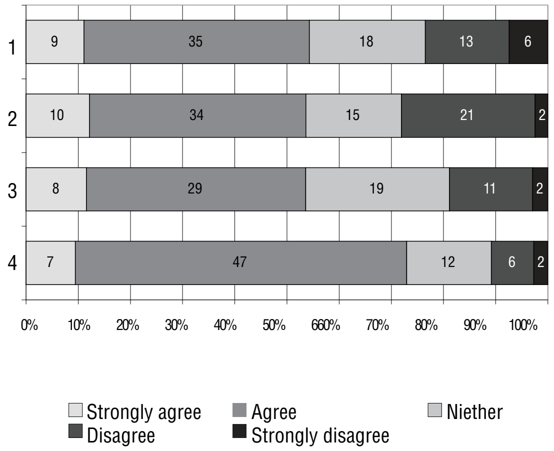
Q7: In practice I am able to uphold the end of life wishes of patients.

1. Pre-test Control Oct 2004 n=81

2. Pre-test Pilot Oct 2004 n=82

3. Post-test Control April 2005 n=69

4. Post-test Pilot April 2005 n=74



Outcome variable 3: Associated job satisfaction

A further statistically significant change was found in the post-test pilot group using the Chi squared test on Q.10, which did not occur in the control (pilot 0.026*, * p <0.05; control 0.658). In effect, 67% of post-test pilot nurses agreed they experienced job satisfaction because in practice they could deliver appropriate end-of-life care compared to 47-53% in the baseline and post-test control groups (table 4.). The combination of this outcome with outcome variable 2 represents `Associated job satisfaction'. The multiple regression analysis showed similar results to the Chi squared test but was not as statistically significant.

Table 4:

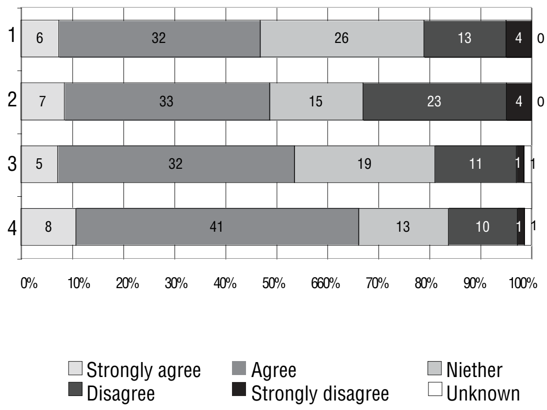
Q10: I experience job satisfaction because in practice I can deliver

1. Pre-test Control Oct 2004 n=81

2. Pre-test Pilot Oct 2004 n=82

3. Post-test Control April 2005 n=69

4. Post-test Pilot April 2005 n=74



QUALITATIVE FINDINGS

Pre-intervention focus group

The pre-intervention focus group sessions were evenly attended by a total of 18 nurses from six of the eight wards involved in the trial, comprising enrolled nurses and registered nurses with the majority being registered nurses.

Although palliative care nurses expressed satisfaction with the end-of-life care their patients received, overwhelmingly concern was about patients suffering because treatment aimed at restoring health was continued when death was imminent. For instance one nurse shared: *'a bad situation with an old person. I saw him take his last breath. It was my responsibility to call the code, but I was just tempted to walk away because he did it so peacefully. But there was no NFR (not for resuscitation) order ... your responsibility is to call somebody. It was really hard to be the one to have him brought back and he died anyway'* (20.10.04).

Another participant said there was a: *'man lying in bed trying to express that he wanted to die, everything we'd try to do for him, he'd fight. Eventually he stopped breathing and we had to resuscitate him... I don't know what happened to him after that. But it was just horrible and I didn't think we should have to do that'.*

Concerns were also expressed that families can be domineering and doctors offer them decision-making power about resuscitation issues: *'the families can't, or won't see that it's coming to an end, and each night you go in there and hope they (the patient) make it through to the next day. The doctors say 'do you want them to be resuscitated?', and the relatives say 'yes we want everything done'. They think resuscitation is what you see on ER (medical television show), or at least that it means that the patient will end up how they were, which already is a sick person with a failing heart and kidneys ... relatives feel guilty if they decide for them and if the patient suddenly arrests you have to do CPR (cardio-pulmonary resuscitation) and it doesn't seem right'* (21.10.04).

A senior nurse continued: *'We attend code blue calls and just the number of calls that you get for people who* *are in their 80s and 90s and who are frail and skinny, they are breaking ribs when they are doing CPR. I'm sure if you asked the person previously that they probably wouldn't want to have this done to them. It could have been a better experience for them and the family'.*

Nurses shared that terminology makes understanding difficult for older people and those with little English. They spoke of how patients are willing to talk about dying and that it should be brought up, but it's hard when curing is the goal.

If you talk to some patients they don't want treatment, they don't want to live, they wait until the doctor has actually left and then they say to you 'I don't want this'. It's that age group, where whatever the doctor says they'll just go along with it. We are in the middle, and often we can explain to the family what washes over and communicate (back) to the doctors (20.10.04). There was acknowledgment *'that it's very difficult for the doctors to be saying 'there's nothing more we can offer you'* (21.10.04).

The nurses disclosed that with no formal pathway for patient advocacy they received an uncertain hearing. One stated that: *'Advocating for patients toward the end can be difficult because our doctors can be so hell bent on treating'.* A senior nurse disagreed saying: *'I certainly think we can advocate, our doctors are quite good'.* Others would not elaborate on why they did not find advocacy easy although one nurse disclosed: *'It's taken me years to get to that point where I feel like I can say anything'* (21.10.04).

Post-intervention focus group

The six month post-intervention focus group was attended by three enrolled nurses, from three of the four pilot wards, all of whom had been trained as RPC consultants. Attendance was low, due to competing training sessions, and time restraints prohibited the conduct of another focus group. Adequate information was gathered from the trained RPC consultants but the session did not capture the perspectives of other nurses on the pilot ward and so their questionnaire comments are mentioned.

The post-implementation pilot focus group participants admitted that in the past initiating end-of-life care discussions risked disapproval or questioning: *'It was like, that's not your role. It was really hard sometimes, to advocate for you patients'.*

They discussed the difference the RPCP made: *'I think it changes the whole culture about what we are doing. It's been something that we do discuss with our patients, but we've never had a formal process for it. Most are very appreciative of it and certainly for people with chronic conditions it's something they've already thought about. They have said 'I'm really terrified of going to a nursing home' and 'What if I can't walk? I don't want to keep going'. Just explaining the different terminologies is giving them clearer goals they can think about then talk about with their families. You feel like you are giving people a chance to make an informed decision. I know that even if I don't agree with it, it's what they want ... knowing what someone actually wants makes me feel safe in providing care to that person'* (20.04.05).

A nurse who had not done the RPC consultant training commented on the questionnaire: *'Since having the RPCP a lot more care and respect is given to end stage patients'.* Another however wrote: *'I have experienced the doctors overriding the patient's choices, to stabilise the patient, which prolonged the dying process'* perhaps *illustrating the position of not being empowered through the RPC training.*

The RPC consultants shared that having a formal process to advocate through meant doing the job corresponding to deep felt ethical conviction. It was described as nursing as it should be. *'Before we had respecting patient choices there were times when you wondered whether you were doing the right thing for your patient. Now you're often finding out whether a patient wants to be resuscitated or whatever as far as their treatment goes. This is back to the philosophy, the foundation of why people want to do nursing, because you want to be a patient advocate. You want to provide comfort, encouragement and education and support your patients through their own process, not your own; now we can act on the patient's behalf and ensure the care provided is what they want and it can be respected, because it is in black and white, it's written down'* (20.04.05).

Limitations

The non-equivalent control group is a limitation as the sample for explanatory research is required to be typical characteristically of the target population so as outcome generalisations can be applied to it. Representativeness was claimed because nursing skills mix and nurse patient ratios are based on Australian Nursing Federation and the Victorian Government Department of Health agreements, while clinical practice standards are determined by bodies such as the Nursing Board of South Australia. The generalisation about background issues is affirmed by the Australian Council on Healthcare Standards action of issuing a draft in October 2005 on a new standard: *'Systems for managing consumer/patients at the end of life are caring and appropriate'* (ACHS 2006 EQuIP 4 program standard 1.17).

Expectancy effect because of the investigator's involvement in the RPCP is minimised through the use of anonymous surveys. Professional advice and assistance from the hospital epidemiologist, biometrician and experienced qualitative researcher served to reduce bias and systematic error in the data gathering. Instrument reliability was demonstrated by the consistent pattern shown from ward to ward on questionnaire responses. The study does not gauge practical effect, nor does it measure outcome sustainability, however corresponding ACP-ing activity is reflected in the hospital RPCP audit data at six months intervention (Box 2.).

Box 2: TQEH audit at six months RPC implementation (April 2005)

- **55% of the 52 RPC consultants commenced ACP-ing discussions.**
- **28% of the 238 patients engaged in discussions made ACPs.**
- **The most ACP-ing occurred in the renal dialysis day unit where 32% of all patients had formulated a plan.**

An ACP included:

- **Legal ADs South Australia: Medical Power of Attorney (MP) and Anticipatory Direction (AD) under the Consent to *Medical Treatment and Palliative Care Act 1995*; Enduring Power of Guardianship (EPG) under the *Guardianship and Administration Act 1993.***
- **Informal advance care plans: Statement of Choices (introduced by the RPCP); Good Palliative Care Plan (developed by the Palliative Care Council of South Australia).**

DISCUSSION

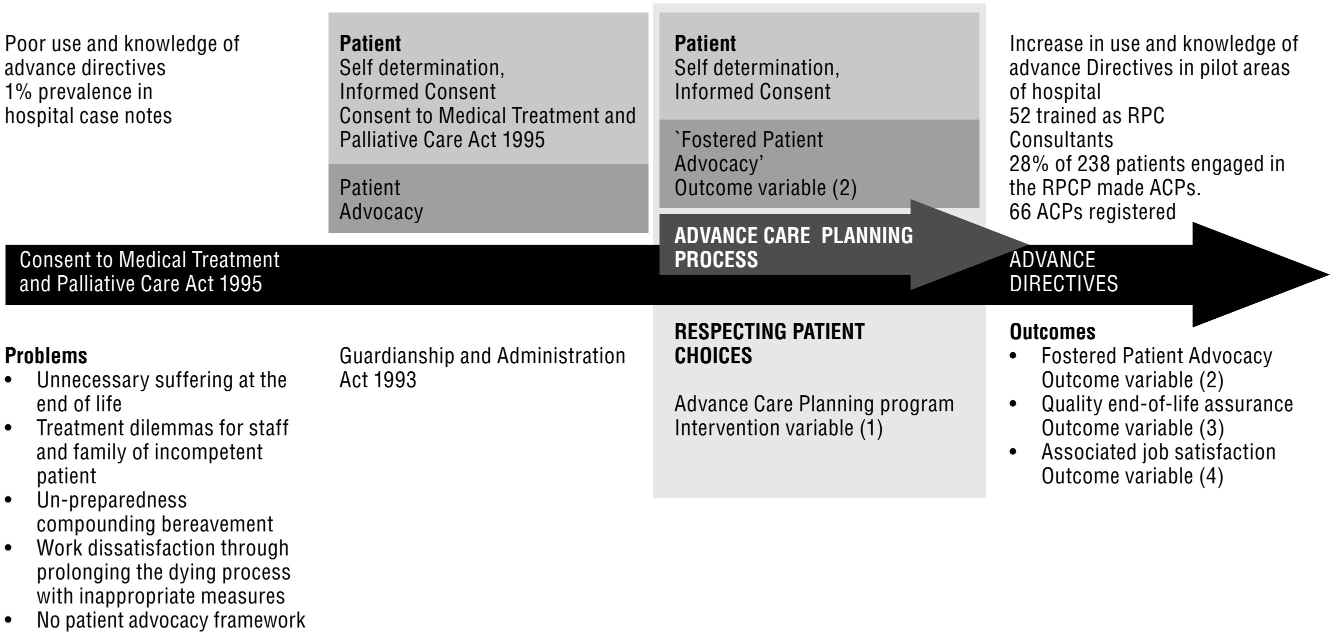
The research revealed that before the RPCP, the majority of nurses did not feel encouraged to ensure patients could exercise self determination regarding their end-of-life care. In addition, approximately half felt they were unable to uphold their patients' end-of-life care wishes and experienced job dissatisfaction because of the inappropriateness of the end-of-life care delivered. The corresponding focus groups provided insight into nurses' concerns about resuscitation, patient vulnerability and uncertainty about advocacy roles.

Nurses in the post-intervention pilot generally agreed they were encouraged to ensure their patients could exercise self-determination regarding end-of-life care (fostered patient advocacy). This finding was statistically significant and the testing technique was explanatory, enabling the prediction that if the RPCP were to be introduced to another sample in the target population similar outcomes should result. Also, end-of-life care was more satisfying because the level of treatment was perceived to be appropriate and congruent with patient's wishes. The corresponding focus group affirmed research content validity and reinforced that outcomes resulted from the RPCP intervention. Being able to provide information to patients while they were still well enough to talk with their families stimulated communication, enabling people to determine their future care and easing their concerns about loss of control. The program provided a legitimate platform for nurses to empower patients and to advocate on their behalf, promoting quality end-of-life in the acute hospital (diagram 1).

Diagram 1:

promoting quality end of life care in the acute hospital setting

- Base line pre implementation of rpcp both pilot and control areas
- Post implementation of rpcp control
- Post implementation of rpcp Pilot area at 6 months



CONCLUSION

The research hypothesis was supported suggesting patient advocacy fostered by the framework and tools the RPCP provides, plays an integral role in effectuating the ACP-ing process with the ensuing outcomes of end-of-life quality assurance and associated job satisfaction. The organisational endorsement of ACP-ing gave nurses the autonomy to be patient advocates reconciling clinical practice with their code of ethics and easing distress about prolonging the dying process inappropriately.

It is recommended that the RPC ACP-ing model be embraced by acute hospitals in the promotion of quality end-of-life care. The RPCP trains and equips nurses to assist patients with the ACP-ing process. It is recommended that patient advocacy attributes, which arise out of care for others, be recognised and developed as integral to this process.

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