

## INTRODUCTION

Apart from anecdotal stories, little is known about what happens to patients after their discharge from Australian intensive care units (ICUs). Do these patients die soon after their discharge or do they recover to live meaningful lives? This lack of knowledge about patient outcomes causes many ICU practitioners to express ethical, economic and social concerns about their clinical practice. These professional concerns are expressed in a variety of ways. The ICU tearoom, for example, is often a place for frustrations, such as the following, to be expressed:

*You know they're not going to make it. And we still do it. Why do we bother? We get these old people who just want to die. We put them in ICU and torture them which is what it is – then we send them to the ward to die. (Cathy)*

*With our salvage mentality, we pick someone out of the gutter, bring them to ICU where we polish their boots using the most expensive boot polish available, then return them to their spot in the gutter. (Mike)*

With concerns such as those expressed by Cathy and Mike in mind, a research project was designed at The Royal Melbourne Hospital's ICU. The aim of the project was to assess patients' health status, functional recovery and quality of life after their discharge from ICU.

The ICU at The Royal Melbourne is a general medical and surgical unit in a large metropolitan teaching hospital; a very busy place admitting approximately 1300 patients each year. This study highlighted the disparities between the provision of health care services.

When patients were critically ill, they had access to state-of-the-art medical technologies and the specialist staff in ICU to 'save their lives'. After discharge from ICU, they had difficulty accessing adequate services to support them to live. Whittaker described this lack of commitment to

support and rehabilitate patients as 'intensive care, no care, then don't care'.<sup>1</sup>

According to the patients and carers interviewed in this study, the high-tech interventions were sometimes used without the commitment to provide the services to ensure an optimal recovery. Julie, for example, was a 40-year-old woman who suffered a sub-arachnoid haemorrhage. After having her life 'saved' with sophisticated neurosurgery and post-operative treatment in ICU, Julie needed to be taught how to walk, talk and feed herself again. She needed a continuity of care to help her thrive, not merely survive.

## TRANSFER TO THE GENERAL WARDS

From the 572 patients admitted to ICU between 1 July and 31 December 1993, 513 patients (90%) were discharged to the general wards. During interviews with patients and their carers, many spoke angrily about the lack of continuity of care. Richard described his struggle in the following way:

*I've had a hell of a time since ICU... The operation saved my life, but then what? (Richard)*

According to Emma's father, the lack of communication between ICU and the general wards was 'unbelievable'.

*The lack of communication between ICU and the ward nearly killed her. It is unbelievable. She was only in the ward for a week and she's back in ICU... There was just no communication. They forgot to order all her antibiotics on the ward and she got pneumonia. Good health care, huh? After all the effort – not to mention all the time and money that was spent to keep her alive. And then to send her into the ward where, because of some poor communication system. I mean, she could well have died and wasted all that time and effort. (Emma's father)*

In this study, there were 67 readmissions (10.5%) to ICU. Although some

readmissions were due to the progression of patients' illnesses or their post-operative requirements, others, such as Emma's readmission, were preventable. The nursing staff were often able to predict which ones would come back.

*We send them out early because we need the bed. What do you expect? Of course they fall in a hole. (Michelle)*

The high readmission rate illustrates the costs incurred when the health care system fails to provide sufficient resources to provide follow-up care on the general wards. Take Robert's story for example:

*But then he got to the ward. Now the ward people are flat out. We understand that. They ran from the moment they started duty... they tried their hardest under terrible circumstances. So I don't blame them. (Robert's daughter)*

In an environment described as 'terrible', it was not surprising that Robert required readmission to ICU. Rather than apportion blame for his readmission, attention must focus on the failure of current health care policies to provide sufficient resources to ensure an adequate number of experienced nurses on the general wards. Although Robert's readmission to ICU was allegedly caused by the failure of the nurses on the ward to aspirate the nasogastric tube, the more serious failure was the lack of supervision of junior health care practitioners by senior staff on the general wards.

After spending an additional week in ICU and a further ten days on a general ward to recover from aspirational pneumonia, Robert (an 80-year-old man with an 80-year-old wife) was transferred home without any follow-up support services arranged. At no stage was he referred to either a social worker or an occupational therapist. His daughter, who had to resign from her full-time paid job to care for her father, expressed her frustration in the following way:



**THE INITIAL  
PROPOSAL STATED  
THE RESPONSIBILITIES  
OF THE CLINICAL  
NURSE CONSULTANT  
AS FOLLOWS:**

- > To establish a relationship with patients and their families whilst patients are in the intensive care unit;
- > To liaise with a multi-disciplinary team regarding the care of patients whilst in the intensive care unit and maintain good communication. Establish and maintain communication with local health professionals, including general practitioners;
- > To ensure that families remain well informed;
- > To provide at least one follow-up visit to all patients after the patient has been discharged to the general ward. This visit will indicate whether there is a need for further follow-up. If so, to provide the necessary follow-up that is deemed appropriate;
- > To continue to liaise with the multi-disciplinary team during the patient's hospital stay;
- > To assist in the early identification of problems that may lead to the patient being readmitted to the intensive care unit and, where appropriate, to implement action;
- > To establish the collaborative development of an early discharge plan with patients, families, the appropriate members of hospital staff and local community support networks;
- > To maintain contact with the patients' general practitioner to discuss the critical illness and the discharge plan;
- > To provide written documents to the relevant community workers;
- > To provide the opportunity for patients and their families to attend debriefing sessions at an appropriate time;
- > To contact patients soon after their discharge from hospital to ensure that they are receiving the necessary support; and,
- > To organise any further support that is deemed necessary.

– Dr Sarah Russell

*Where was he meant to go? They were supposed to be looking after him. (Robert's daughter)*

It is perhaps not surprising that a few weeks after his discharge home, Robert required an emergency readmission to hospital with a chest infection. He was not only one of the 67 readmissions to ICU, but also one of the 101 unplanned readmissions to hospital during the study period.

**DISCONTINUITY OF CARE**

Although 425 patients (75%) were known to have survived six months, and 85% of these survivors were living at home, many patients interviewed in this study were not thriving. Living at home did not imply a successful outcome for patients. It merely made an unsuccessful outcome less visible.

To ensure an optimal recovery, studies have shown the importance of follow-up support in the community.<sup>2,3</sup> Without adequate follow-up, recoveries were not only diminished but it was also costly for families and the community. In this study, only 166 patients (29%) were assessed by a social worker. This resulted in many patients being discharged home without any follow-up services arranged. Instead, untrained carers were frequently expected to perform tasks, such as wound dressings and the administration of medication, for which they had no expertise.

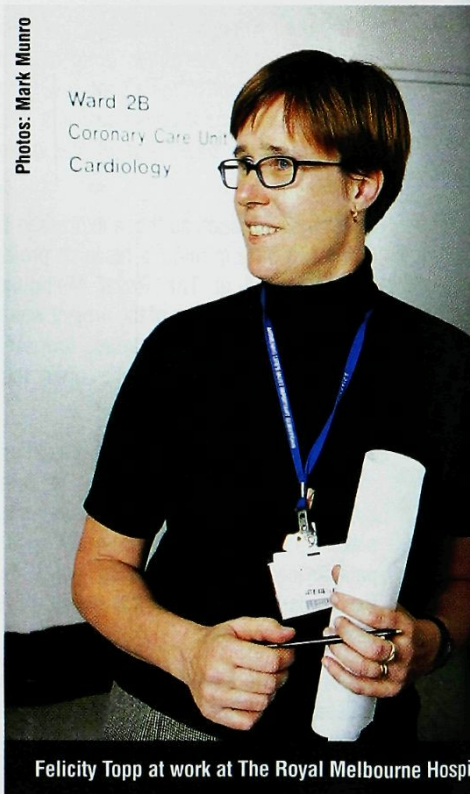
After discharge home, family members frequently provided caring duties in the home that were once provided by qualified health professionals within hospitals. John's wife, for example, did not consider nursing duties to be her 'place'.

*I didn't think it was my place to be doing the dressing. He had a discharge. It was dreadful. I wasn't to know whether the discharge was serious or not. I'm only a mother, not a nurse. Anyway, I watched them (the district nurses) do it and I learnt how to do it myself. They only did the dressing once a day, but I did it twice. He couldn't lay in a wet bed. It was oozing all the time. The bed would get messy. So it seemed better to do the dressing more often. (Patient 486's wife)*

It was often taken for granted that family members would be available, willing and able to undertake the duties of caring after a patient was discharged from hospital. Yet this was often not the case. Given the diversity of family and household structure, many of the assumptions about family members being available to provide the necessary care for dependent relatives at home were mistaken.

After discharge home, some patients in this study required only minimal assistance for a short period of time. There were, however, 175 respondents (57%) who acknowledged that they continued to require assistance with activities of daily living. Yet only 19% of these people used community support services.

Most relied on family members, especially female family members, with little or no support from the 'community'. This transfer of responsibility for the care of sick people onto unpaid and unqualified labour had serious implications for both patients and their families.



Felicity Topp at work at The Royal Melbourne Hospital



**CONCLUSION**

When a patient experiences a critical illness, a range of health care services are required. As part of a continuum of health care services, ICUs are merely one among many health care sites that need to be provided to assist patients' optimal recoveries. Yet, it is often argued that ICUs are the most important health care site because they 'save lives'.

Health professionals who hold this view fail to appreciate the benefits of preventative and ongoing health care in the community. ICUs are dramatic; without the intervention an individual dies. Preventative services also 'save lives', but the deaths involved are less instantaneously noticeable and so less dramatic.

Given the hierarchy that has been established within the health care system, Jackson suggests that the health budget will continue to be dominated by high-tech acute care, with the rest of the system expected to survive on 'women workers, good will and cake stalls'.<sup>4</sup> As a result, patients have access to sophisticated life-saving procedures in ICU but not to other less intensive services that may help them to live.

In this study, the lack of professional follow-up care had serious implications for patients' recoveries after discharge from ICU. It also contributed to a number of unnecessary and costly hospital readmissions.

**REFERENCES**

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**\*Note: the names used in this study have been altered to protect the identity of the patients involved.**



## BRIDGING THE GAP

### THE ICU AT THE ROYAL MELBOURNE HOSPITAL HAS RECENTLY EXPANDED ITS CLINICAL NURSE CONSULTANT ROLE.

As a critical care nurse, Sarah Russell became acutely aware of the problems faced by patients once they left the ICU. Resources on the wards were often stretched to the limit, and basic tasks were sometimes left undone in the mad scramble that was a daily ward shift.

She saw patients who had left the comfort of a high-tech, state-of-the-art environment into a situation where they had problems gaining access to even the most basic services. Occasionally, she saw people who were being readmitted to the ICU when they should not have been.

After doing research about 'life after the ICU' for patients at The Royal Melbourne Hospital, which included interviews with patients and their families, she decided to do something about the problems they faced.

In late 1994, she lobbied the hospital to create a new

clinical nurse consultant position to act as a 'follow-up' to directly help patients who were being discharged from the ICU.

'Preventable readmission rates were the number one problem,' she said.

The hospital agreed with the need for such a role, and the position was created in 1995, initially part-time, with the goal of establishing a relationship with patients and their families during their stay in the ICU.

Other aims were to liaise with the multi-disciplinary team about the patients' care and to provide at least one follow-up visit after the patient had been discharged to the general ward, and to provide any 'necessary follow-up that is deemed appropriate'.

After three years, the position has become a permanent fixture in The Royal Melbourne Hospital ICU and in 1999, two part-time positions are planned to provide seven-day a week cover.

Readmission rates to the ICU also have been falling, from 10.5% during the original 1993 study to 8.5% in 1995.

Although Dr Russell is keen to point out there has been no research to prove a direct correlation between the position and falling readmission rates, it is at the very least a happy coincidence. She is now working at getting similar roles established at other Melbourne hospitals.

Felicity Topp has been the 'follow-up' nurse for six months and will take one of the new part-time positions.

'I am the link that follows them (the patients) out of the

ICU,' Ms Topp said.

'I have to try and foresee the needs of the patient once they leave the ICU.'

Her duties include everything from grief counselling to organising accommodation and airlines for family members visiting from country areas or interstate.

Ms Topp tries to attend one of the two daily rounds in the ICU, and makes a point of attending family meetings, which she says are particularly important.

'I spend the most time talking to families when the patient is in the ICU... when people have been traumatised by the experience or they don't remember it, and I spend time when they are in the ward and try to validate their experiences.'

She describes the role as somebody trying to 'bridge the gap'.

'The medical staff want that communication but they are often either in theatre or too busy doing something else. To have somebody having that constant communication is very important.

'You need to have somebody to be there with the family after the doctor has met with them to explain what they didn't understand because there is so much information and they are so stressed,' she said.

Ms Topp is able to draw on her ICU background as well as qualifications in counselling to deal with the constant anxieties that are created by people who have to go into the intensive care setting.

- Dimitri Serghis