

Residential Aged Care

Communiqué

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EDITORIAL

Welcome to the final issue of the RAC Communiqué for 2014. It is a bumper issue with a supplement to cover the complex topics, goals-of-care and end-of-life in Residential Aged Care Services. With the supplement we present four cases, four commentaries and a detailed list of resources.

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The cases highlight different aspects of care at the end-of-life and some of the challenges around discussing these matters. Our expert commentaries cover a range of experiences. Three of the commentaries are written by medical practitioners, two are specialists in palliative care, one is a general practitioner and the final commentary is from Professor Rhonda Nay who as we all know is one of Australia's leading academics in aged care and formidable advocate for better care of older people.

It is curious that not so long ago, everyone was marvelling at the advances in medical science leading to a universal requirement or expectation to provide cardiopulmonary resuscitation. This was the 1970's, a time when Intensive Care and Coronary Care Units were becoming widely established. Twenty years later, in the 1990s, we recognised that sometimes care could be futile and that setting limits around life-sustaining therapy was a reasonable concept. Another twenty years on, in the 2010's we see models of shared decision-making with patients and residents, the introduction of advance care planning and National Standards for acute care hospitals to ensure goals-of-care are completed.

Any discussion about goals-of-care and end-of-life generates controversy and debate. Although this is a bumper issue, we still cannot cover all aspects of the topic. However, this should not distract us from ensuring we better understand the purpose and processes involved in providing care for our residents evident from these cases and commentaries.

A YOUTUBE VIDEO: NOT FOR RESUSCITATION

FREE SUBSCRIPTION

The Department of Forensic Medicine, Monash University will publish the **RESIDENTIAL AGED CARE COMMUNIQUÉ** on a quarterly basis. Subscription is free of charge and the Communiqué is sent to your preferred email address.

If you would like to subscribe to **RESIDENTIAL AGED CARE COMMUNIQUÉ**, please signup on our website at www.vifmcommuniques.org/subscribe

This is animated YouTube video presenting the topic of "not for resuscitation" and dementia. It is just under ten minutes long and is intended as a thought provoking introduction to a small group discussion within your clinical team. Preview the video at <http://www.profjoe.com.au/all-cases-list/to-resuscitate-or-not/> and let us know your thoughts.

Next issue: February 2015



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FEEDBACK

The editorial team is keen to receive feedback about this communication especially in relation to changes in clinical practice. Please email your comments, questions and suggestions to:
racc@vifm.org

DISCLAIMER

All cases that are discussed in the Residential Aged Care Communiqué are public documents. A document becomes public once the coronial investigation process has been completed and the case is closed. We have made every attempt to ensure that individuals and organisations are de-identified. The views and conclusions are those of the authors and do not necessarily represent those of the Coroners, Department of Health, Victorian Institute of Forensic Medicine or Monash University.

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CASE #1 NFR NO MORE

Case Précis Author:
JE Ibrahim, Monash University

Clinical Summary

Ms E was admitted to a regional acute hospital after a fall at home and was diagnosed with a urinary tract infection and a small subdural haematoma. Past medical history included: Alzheimer's disease, atrial fibrillation, hypertension, ischemic heart disease, osteoarthritis and chronic kidney disease. After being in hospital for about seven weeks it was clear Ms E had not recovered sufficiently to return home and was transferred to a RACS.

At that time Ms E required full assistance with personal care and had a MMSE score of 13/30. A standard form for 'goals of care' was completed on admission to the RACS indicating Ms E was for "transfer to acute care for treatment but not for intensive care or cardio pulmonary resuscitation."

Ms E was transferred to acute care several times over the next two years for: surgery on a hip fracture; sepsis and deep vein thrombosis; chest infection and dehydration; bradycardia and lethargy due to medication toxicity. The goals of care were re-examined each time. On this last occasion (February), a new directive was completed and signed by her son (power of attorney) and the medical practitioner, indicating Ms E was for full cardiopulmonary resuscitation.

Six months later (July), Ms E's developed a productive cough and was transferred to an acute care hospital, the son told the ambulance officers that Ms E was for full resuscitation. Ms E was diagnosed with myocardial infarction and aspiration pneumonia. The family requested continued adherence to the full resuscitation status. As Ms E's condition continued to decline, the family held discussions with the clinical team and continued to ask that in the event of deterioration the intensive care team should be called. At this point the medical practitioner requested an ethics consultant to support the family in their decision-making.

This led to a change in the goals of care to do not resuscitate and Ms E died three days later.

Pathology

There was no autopsy.

Investigation

Further investigation was required because of concerns raised about the communication and documentation of the decision making process related to Do Not Resuscitate orders. Ms E's son also expressed concern about the order

being made without his mother's consent. The investigation revealed a number of interesting features.

First, there was no documentation as to why the goals of care were changed in February. However, there was a note (from May) that Ms E's daughter said she would speak to her brother about the goals of care.

Second, there was no evidence that the family were informed of Ms E's poor prognosis and the futility of intensive care or resuscitation. This was important as Ms E's condition continued to decline during her stay at the RACS. Ms E's cognition deteriorated as the dementia progressed developing behavioural and psychological symptoms of dementia as well as suffering multiple falls, swallowing difficulties and intermittent lethargy.

Third, during the final hospital stay, the family understood that an ICU stay would not offer their mother a chance at meaningful quality of life, and the family felt obliged to respect their mother's previously expressed wishes.

Coroner's Comments and Findings

That RACS staff and health care providers be reminded that the process of consent for goals of care and advance directives must be well documented including the documentation of provision of appropriate information to substitute decision makers to allow for meaningful decision making. Especially important was the documentation of revocation of these orders with an explanation.

RACS should ensure that they have policies detailing the procedures to be followed by teams in the process of communication and documentation related to advance care planning. This includes a process for ensuring that the most recent and relevant decisions are clearly indicated and readily apparent in emergencies, at times of transfer to acute care and at other transitions of care.

Editor's Comments

This case illustrates that situations are rarely what they seem on the surface. Whilst it was clear the family understood the medical staff explaining the technical aspects of treatment and the poor prognosis, they were not behaving in a manner that matched that knowledge. It must have been an incredibly frustrating time for the family and the clinical staff, and the impasse could only be negotiated by understanding that the family was following what they believed were their mother's previously stated views.

CASE #2 ANOTHER FAMILY MEETING

GLTCRC 2012 (2012-09)

Case Précis Authors:

C Young RN, Ballarat Health &
JE Ibrahim, Monash University

Clinical Summary

Mr J was a 71 year old male community dweller who lived at home with his wife. Past history included: multiple strokes and Vascular Dementia, behaviours of unmet needs, complex partial seizures, ischemic heart disease requiring coronary artery bypass graft surgery, diabetes mellitus, osteoarthritis of hip, knees and shoulders and throat cancer.

Four days after Christmas, Mr J was taken to an acute care hospital emergency department due to increasing physical aggression. Mr J's wife explained she could no longer manage to provide care at home. Mr J was admitted and diagnosed with significant dementia and frontal lobe-related dis-inhibition.

About one week later, Mr J was admitted to a restorative care where a family meeting was held to determine options for future care and accommodation. Over the next fortnight, Mr J's cognition fluctuated, his wife explained to staff he often sounded confused and distressed "talking about guns and thought he was going to jail". Mr J also had several falls but preferred to walk alone with his gait aid and also to shower without assistance.

Late in January, Mr J was found on the floor of the shower unconscious. An urgent CT scan of his brain revealed multiple intracranial haematomas with midline shift. There was a discussion with his family and the decision made "not for resuscitation" and to provide comfort measures. He died the next day.

This case was investigated because of concerns about supervision and communication with the family. No serious concerns were identified.

Editor's Comments

We included this case as it demonstrates that there are a number of opportunities to raise questions about escalation of care, goals-of-care and end-of-life issues. Mr J's family participated in at least three formal family meetings to discuss care. The focus had been about the immediate care issue of behaviour and accommodation. The staff had recognised and assessed the risks of falls, and respected Mr J's desire to be independent in the shower.

How would you have handled this situation?

Would you have done anything differently?

Should there have been a discussion about end-of-life care in those family meetings?

It is easy in hindsight to say, 'yes of course'—the reality is often different with most of us doing our best to get through the issues of the day rather than forecasting what might occur and helping each other prepare for that future.

COMMENTARY #1

IT IS EASIER TO READ NOTES THAN TO READ MINDS

Dr. Nyree O'Connor FRACGP

General Practitioner, Bacchus Marsh

The end of life is something few people want to think about and so even we often put off talking about the care that is desired at the end-of-life. End of life care is something that should begin well before a person dies.

End of life care is a continual process, requiring informed decisions that are negotiated, made and reviewed as circumstances change. We should involve patients, their family, appointed substitute decision makers (SDMs), carers, nursing, medical and allied health staff.

We should also recognize that some decisions can and are made in preparation when planning for the end of life, whilst other decisions are made in response to new issues as these occur. So always consider whether a decision is needed for an actual or hypothetical situation. Do not get locked into a situation where you are trying to ask and answer every possible hypothetical question.

End of life care is something that should begin well before a person dies.

The actual end of life is a stressful time for SDMs, families and sometimes patients. We know that preparation reduces stress and anxiety and improves one's ability to make decisions under pressure. This is one of the reasons why it's important, where possible, to discuss end of life with these key stakeholders in advance, and formally document any decisions made in an Advance Care Directive (ACD).

In the community Advance Care Planning happens sporadically, but patient and doctor awareness is increasing and so is the uptake of ACDs. In residential aged care services, admission is the

perfect time to initiate Advance Care Planning and to document an ACD. In both settings, any significant change in a patient's health should prompt the revision of the ACD.

We also know that despite the best preparation unforeseeable situations occur. When this happens at the end of life, a previous ACD may no longer be appropriate for the situation. SDMs may feel conflicted – on one hand they're trying to respect the patient's wishes, but on the other they may be being told that treatment is futile and should be withdrawn. The SDM can be helped through this with sensitive, informed discussion and support.

In residential aged care services, admission is the perfect time to initiate Advance Care Planning...

Discussion should be about quality of life, risks, benefits and futility of treatment, and the fact that decisions change as circumstances change. It is important to remind SDMs that an ACD was made when the patient had a specific set of health problems, and that once these health problems change, it is appropriate to change end of life management.

Sometimes SDMs just need to be given permission to do this. It is often helpful to involve spiritual and faith based advisors, counsellors and palliative care staff in these situations. These services are especially helpful if additional support is required to cope with grief, carer stress and burnout.

It is when everybody understands what decisions have been made and why, that the patient receives the best care possible...

Whilst discussion is important, it is of no benefit to others involved in a patient's care unless it is documented thoroughly. The situation is already stressful enough and we do not want to compound this with miscommunication, misunderstandings between clinical and care staff that flow on to mixed or even worse contradictory messages to the resident and family. As a general practitioner I rely on the charts, notes and documents in the resident's file to gather information about what each resident has been told and who is involved in care.

It is when everybody understands what decisions have been made and why, that the patient receives the best care possible and is enabled quality of life and to die with dignity.

COMMENTARY #2 SYMPTOM MANAGEMENT AT END-OF-LIFE

Dr Jaclyn Yoong MBBS (Hons), FRACP,
FACHPM

Medical Oncologist and Palliative Care
Physician

Northern Health & Eastern Health

As a visiting medical specialist in palliative care to RACS, I have seen a range of approaches to residents. Most RACS and their staff want to get it right for their residents.

Symptom management at the end-of-life remains a challenging area...

One really positive experience I had was with a 92-year-old gentleman with a pathological fracture of the hip from metastatic cancer. This man was bed-bound, frail and surgery was deemed too dangerous. The pain from the hip fracture was excruciating especially on movement. When I attended, the general practitioner had already seen him and prescribed a pain relieving medication patch to minimize the pill burden, and the staff were judiciously administering additional analgesia prior to care procedures such as bed turns and for hygiene.

...we need to work together to improve is the liaison between RACS and acute health services...

Symptom management at the end-of-life remains a challenging area in hospitals, the community and at RACS. We see and do our best to manage the commonly experienced symptoms of pain, nausea and vomiting, shortness of breath, agitation, confusion and mood disturbance.

Optimal management requires the availability of staff with the necessary skill sets, including medical (general practitioners, specialists in palliative care), nursing and other care staff who are able to provide comprehensive and insightful assessments, as well as appropriate management.

A standard approach to assessing symptoms includes assessing site, severity, duration, nature, and triggering and relieving factors. Symptoms should also be assessed for cause, which is often multi-factorial. All the contributing causes should be managed and tailored to the needs of the individual resident. The use of pain charts, behavior charts and regular observation for other symptoms are especially helpful.

Medication use is especially important in RACS where the residents are often 'tricky' to assess, typically uncomplaining and often non-verbal as well as being frail. They often have multiple co-morbidities and are more vulnerable to side effects of medications (e.g. we would not recommend the use of morphine in residents with worsening renal function). Judicious prescribing, continual monitoring and reassessment are necessary to ensure the desired response and avoid side effects. There are also negative perceptions of some medications (e.g. morphine) by patients and families that we need to be prepared to discuss.

A major area that we need to work together to improve is the liaison between RACS and acute health services, especially around better communication and ensuring a common understanding around the goals of care for residents.

The use of pain charts, behavior charts and regular observation for other symptoms are especially helpful.

The management of palliative care is an area we should all strive to improve and the timing is right now. There are resources available for education and training for RACS staff relating to symptom management, including written materials, online resources, as well as seminars and courses offered by local hospitals and professional associations. A proactive stance to improve care in this area would include encouraging awareness, increased training and staffing, regular and continuous medical education, in-services at the RACS by experts in the field, and improved communication and integration with both acute and palliative care services.

My final thought is if you have any issues with clinical care in residents at end-of-life contact your regional palliative care team.

THE FUTURE OF THE RAC COMMUNIQUÉ

This issue is the final one for our longest serving managing editor Fiona Kitching, who is often the first contact for our subscribers.

We sadly bid farewell and Fiona goes with our best wishes to a new position as a practising health professional in another state.

Fiona is working with our incoming managing editor Alex Gillard and together they have designed a production schedule for the next 12 months to ensure a smooth transition.

I would also like to acknowledge the Department of Health (Victoria) Ageing and Aged Care Branch, who have provided funding to support the production of the RAC Communiqué each year since 2006. We are looking forward to our 10 year anniversary in 2015

FIONA'S GOODBYE

I wish all of our readers the best as I leave the editorial team to pursue full time clinical work in 2015. I have helped manage the RAC Communiqué since 2007, and the most difficult job, by far, has been persuading our esteemed editor to keep to our timelines!

It is with sadness that I hand the reigns over to Alex but I am confident that the editorial team will continue to bring thought provoking stories and experiences to our attention.

I now look forward to receiving the Communiqué as a subscriber, which will appear (on time, of course) in my inbox!

Fiona Kitching