MONASH University

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RESIDENTIAL AGED CARE COMMUNIQUÉ

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CONTENTS

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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.

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Next Edition: December 2011

EDITORIAL

Welcome to our third edition for 2011 in which we discuss the contentious issue of risk, rights and responsibility. This edition is a joint initiative with VMIA Risk Management & Insurance who publish a similar newsletter, "Lessons Learned", reporting on clinical incidents.

We present one new case in detail about a resident who died whilst smoking a cigarette and three commentaries exploring different perspectives from: the nursing and care staff; an ethicist and; a resident's advocate.

We do not have "the answer" for you. We do provide a way to discuss how you may want to approach a similar situation.

LESSONS LEARNED

VMIA Newsletter "Lessons Learned" available at:
http://www.vmia.vic.gov.au/Risk-Management/Clinical-risk/Case-studies.aspx

This contains clinical case reports of incidents reported to VMIA. Well worth a look. It has a different approach and presentation from our RAC-Communiqué and has a greater emphasis on health care.

SAVE THE DATE

Next year, VMIA with RACC and DoH will hold a "Dignity and Risk Management" an expert forum and an education seminar. The forum planned is for early 2012 will host a range of experts to help explore the relationship between maintaining dignity whilst managing the risk in residential aged care. An education and training seminar will follow in May 2012 to help staff working in Residential Aged Care Services manage this complex area.

Register your interest and receive further information by emailing: training@vmia.vic.gov.au with your details. We will provide another update in the December edition of RAC-Communiqué.

QUIT

For those readers who are ready to stop cigarette smoking:
www.quit.org.au/ways-to-quit.aspx

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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.

COMMENTARY #1 WHAT AM I SUPPOSED TO DO?

A CLINICAL STAFF PERSPECTIVE

Professor Rhonda Nay and Dr Deirdre Fetherstonhaugh
Australian Institute for Primary Care and Ageing, La Trobe University

Why do I work in aged care?

For sure it is not for the money! If I was mainly concerned to protect my back then I would not choose to work in such an environment where every day presents me with ethical and moral dilemmas for which I am not adequately educationally prepared.

Management is concerned about spot checks and if I want to keep my job I need to keep this in mind. The family wants no harm to come to Mum but do not understand that personhood involves taking risks and at times dying as a result.

The Mission Statement says we are a person-centred organisation but I am not sure what that means if I am dissuaded from respecting the rights of the person central to care: the resident.

So – what am I to do?

Initially I did what the family wanted and said 'No – that is not safe and we need to take care of you', but then I saw the crushed, angry look in the eyes of this once feisty, independent woman. She was imprisoned – not in a gaol cell controlled by wardens for some crime; but in a body where the control was disease and I the warden. I could not sleep – her eyes haunted me. And so, I believe I did the right thing: I supported her right to make choices and take risks. The outcome in the end may appear shocking to some, but I can sleep now as her eyes say 'thank you'. I feel safe however in the fact that I undertook regular risk assessments and put into place strategies to mitigate the risk and minimise the harm where appropriate.

I need more support to help me work through the dilemmas I face here. Management could help by offering more direction and perhaps regular discussions about ethical situations. I think we could do better in terms of working constructively with families so that they understand the importance of supporting Mum to take risks and the potential consequences both of taking and not taking risks.

When I see the look in the resident's eyes when I support her decision and enable her personhood, I would not swap jobs for any money!

Working 'at the frontline' in aged care presents staff with constant moral and ethical dilemmas – by definition there are no simple answers; but there are some resources and guidelines for ethical decision making that can help.

EDITORS COMMENTS

Dr Deirdre Fetherstonhaugh also wrote a commentary by "Dignity of risk" in the RAC Communiqué Vol 5 Iss 1 Feb 2010. This provided tips on how to approach the complex situation.

A QUESTION OF RIGHTS AND RISKS

Case Number: available on request

Case Précis Author: Dr Nicola Cunningham, Victorian Institute of Forensic Medicine, Department Forensic Medicine, Monash University

CLINICAL SUMMARY

Mrs H was a 78-year-old female who lived at a residential aged care service requiring high-level care. Past medical history included dementia and a heavy smoker of up to thirty cigarettes a day. Over the past few years Mrs H's mobility and manual dexterity had declined to a level where she was wheelchair bound and required full assistance with transfers. Mrs H also suffered stiffness and paralysis in one arm and difficulties using her other hand.

Mrs H was unable to light her own cigarettes or bring the cigarette to her mouth. She would smoke by leaning forward to meet the cigarette or holding it in her mouth for long periods of time. Mrs H would extinguish the cigarette by flicking the butt into a nearby container of water.

On this particular day, Mrs H rang the communication bell shortly before the evening meal. Two carers attended and took Mrs H outside, lit a cigarette and left her alone to smoke. Minutes later, Mrs H was found ablaze by staff. She was transported by ambulance to hospital, assessed to have non-survivable injuries and died that evening.

PATHOLOGY

The cause of death following a post mortem examination conducted by a forensic pathologist was severe burns. Neuropathological examination findings were consistent with Alzheimer's disease.

INVESTIGATION

At the inquest, Mrs H's son and daughter (her legal guardians) both gave evidence. Evidence was also heard from the Care Manager (who supervised the staff), the two carers who had taken Mrs H outside, and her general practitioner. The coroner explored the factors that had influenced the decisions and actions surrounding Mrs H's smoking habit. In particular, the inquest focused on the issues of the smoking location, the supervision of residents who smoked, and the specific risks to Mrs H.

The coroner heard that residents had complained about cigarette smoke in the vicinity of their rooms when Mrs H and her son smoked together on his visits, prompting the facility to consider banning smoking. Mrs H's son believed that he and his mother had a right to smoke at the facility, and she would become abusive if not allowed to smoke, so staff agreed to smoking in an outdoor area. When her son or daughter was present, Mrs H was accompanied while smoking. At other times, she was left alone outdoors because of the frequency of her demands, staffing levels, and the interpretation by staff of the type of supervision required. Mrs H's family had not been made aware of this practice and thought that their mother was supervised on every occasion.

The coroner heard descriptions of how Mrs H would forget she had a cigarette in her mouth and ask for another, or would let the cigarette burn down to her fingers, or drop ash onto her lap while holding the cigarette in her mouth.

Following an incident where holes were noticed in her nightdress, staff suggested wearing a fire retardant apron while smoking, Mrs H refused.

It was conceded that staff had been allowing Mrs H to smoke outside with no apron and no supervision.

The Care Plan that had been drawn up on Mrs H's admission to the facility was tendered in evidence. The notations "supervise while smoke", followed on a later date by, "danger to self with burning clothes when smoking…Remind resident to wear a fire protection apron" were discussed in light of the significant deterioration in Mrs H's cognitive condition and physical impairments.

The facility provided details of measures that had been taken since the incident to address the risks associated with smoking by residents. The level of supervision had been explicitly defined as staff being required to remain with the resident throughout the smoking activity. Residents were no longer permitted to keep cigarettes in their possession. There was also a change to the design of Care Plans to ensure that any amendments would be effectively drawn to the attention of the staff. A smoking risk assessment form had been introduced to document features of a resident's medical conditions or smoking habits that may affect their safety.

CORONER'S COMMENTS AND FINDINGS

The coroner found that Mrs H suffered fatal burns when her clothing accidentally caught alight while smoking in a designated outdoor area, and that the lack of supervision was a clear contributing factor in her death.

The Coroner made a number of recommendations including the need for risk assessments to be made of all residents permitted to smoke on premises.

The coroner recommended that the formulation of a Care Plan and the details of any changes that are made, as well as any procedures and practices maintained by a facility regarding a resident's smoking habit, must be properly documented and communicated to all staff and family members. *"Any facility that chooses to permit its residents to smoke…should ensure that in the case of each individual smoker the risk of harm to the resident, having regard to the level of dementia, the loss of manual dexterity of the resident and other matters relevant to the ability of the resident to smoke safely,…. and thus the need for and level of supervision, is properly assessed".*

EDITORS COMMENTS

You may recall a case we described last year in the RAC Communiqué Vol 5 Iss 1 Feb 2010 "Smoking is always dangerous" where an 81-year-old female resident requiring low-level care who was a heavy cigarette smoker, died of thermal burns while attempting to light a cigarette.

Following that death the RACS made a number of improvements including changes to the designated smoking area; a fire retardant apron for aged care residents; having easily accessible fire blankets; removing soft chairs from smoking areas; and training for staff in fire evacuations and emergency responses.

Another interesting development is changes to the law in Australia to mandate self-extinguishing cigarettes. See: http://www.abc.net.au/news/2010-03-18/self-extinguishing-cigarettes-law-welcomed/370194

COMMENTARY #2 THE ETHICS OF JUSTICE AND AUTONOMY

Associate Professor Justin Oakley

Director, Centre for Human Bioethics, Monash University

The ethical issues raised by aged care residents engaging in risky behaviour are well illustrated by the tragic death of Mrs H. The risk of harm in such circumstances raises ethical issues for carers at three broad levels – the promotion and protection of residents' best interests, respect for residents' autonomous decisions, and justice in the allocation of scarce resources (such as staff resources).

In my view, the primary ethical obligation of carers is to act in residents' best interests. However, carers must also ensure that whatever approach they take in serving a resident's best interests they do not violate the resident's autonomy, nor involve treating other residents unjustly. In other words, carers should act in residents' best interests, but respect for residents' autonomy constrains the methods that carers can legitimately use to serve residents' best interests.

What respecting a resident's autonomy requires will depend on their capacity for autonomous decision-making.

This means that, generally speaking, carers should not prevent residents from engaging in risky behaviour, when a resident has sufficient decision-making capacity to do so, but that carers have an ethical obligation to put in place safeguards to protect residents in such circumstances from seriously harming themselves. The level of safeguards ethically required here will also depend on what level of resources that justice would allow a health care provider to devote to one resident, rather than to other residents. (So, some beneficial safeguards that could be used in protecting one resident may unjustly take resources away from other residents who may have stronger ethical claims to those resources.)

It is not uncommon for aged care residents, whether or not they have dementia, to engage in activities that risk harming themselves, such as smoking. Sometimes such activities have considerable personal significance for a resident, as they seemed to for Mrs H, who appeared to particularly enjoy smoking, even when she was alone.

Mrs H seemed to have some cognitive impairment due to dementia, and her mobility and dexterity were somewhat limited. It is not clear to what extent she understood the risks in smoking alone, but there seems to be some level of autonomy in her requests to be taken outside in order to smoke. Therefore, it seems ethically acceptable for carers to facilitate this request, so long as sufficient safeguards – such as adequate monitoring – were in place. It is not clear why Mrs H refused to wear a fire protection apron while smoking, but as the Coroner acknowledged, a smoking apron seemed in any case an inadequate substitute for supervision here.

However, justice in allocating staff resources between the needs of other residents may well entail that carers are not ethically obligated to facilitate a resident's requests to engage in risky behaviour on every occasion.

Refusing an autonomous request from a resident on grounds of justice does not constitute a violation of that resident's autonomy, as a resident's autonomy is violated when it is restricted unjustifiably. The ethical requirement to respect residents' autonomy demands that carers do not unjustifiably restrict the autonomy of residents, but a refusal on grounds of justice is not an unjustifiable restriction of autonomy.

COMMENTARY #3 ADVOCACY FOR THE INDIVIDUAL

Fiona Navilly

Aged Care Advocate, A.C.T. Disability, Aged and Carer Advocacy Service

The principles that guide our advocacy for individuals in RAC are premised on The Charter of Residents' Rights and Responsibility and fleshed out by the Standards and by the broader legislation in which both are contained.

Therefore:

- Facilities are required to provide sufficient staff to meet the needs and preferences of residents;
- A resident's preference and need to smoke must be taken into account and be respected, free of cultural and/or moral judgement as for any other preference or need such food or mobility;
- A resident should not be, or have the perception of being subject to, discrimination or victimisation as a result of their smoking habit, nor should they be obliged to feel grateful for the meeting of their preferences and needs;
- The resident maintains control over decisions relating to, and actions of their daily life. (However, increasingly RACS are considering banning smoking or insisting that cigarettes are not kept in the possession of the owner but are controlled by staff. This practice requires close scrutiny and consideration as to whether it infringes resident rights);
- The resident needs to be supported to maintain their independence. Where risk assessment has recognised a need for supervision then it must be provided in a respectful manner that displays a culture of acceptance of individual preference;
- The provision or withdrawal of cigarettes, the resident's preference/need, should never be used as a reward or punishment. (This practice is reported to advocates and illustrates an existing culture of control).

Advocacy will raise the questions: "When does lack of sufficient staff to meet the preferences and needs of residents become an injustice to those whose needs are not being met?" "What training and support for care staff?" "What cultural and architectural shifts are required in RACS facilities to alter the norm that accepts we do not have enough staff to accommodate this resident's preference?"

LIST OF RESOURCES

1. Charter of Residents Rights and Responsibilities available at http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-publicat-resicharter.htm
2. Australian Nursing and Midwifery Council Code of Ethics for Nurses in Australia 2008 available at http://www.anmc.org.au/userfiles/file/New%20Code%20of%20Ethics%20for%20Nurses%20August%202008.pdf
3. Fetherstonhaugh, D., & Garratt, S. (2008). Supporting families and friends of older people living in residential aged care: Australian Centre for Evidence Based Aged Care (ACEBAC).
4. Nay, R. Bird, M. Edvardsson, D. Fleming, R. & Hill, K. (2011). Person-centred care. In R. Nay & S. Garratt (Eds.), 3rd Edition Older People: Issues and Innovations in Care (pp. 107-120). Sydney: Elsevier Australia.
5. Nuffield Council on Bioethics, (2009) Dementia: Ethics Issues available at: http://www.nuffieldbioethics.org/sites/default/files/Nuffield%20Dementia%20report%20Oct%2009.pdf
6. Past editions of the RAC Communiqué worth exploring in aged care around clinical risk available at: http://www.vifm.org/education-and-research/publications/residential-aged-care-communique/> include:-
    - Restraint:- Vol 1 Iss 1 October 2006
    - Falls:- Vol 2 Iss 1 March 2007
    - Unmet needs:- Vol 5 Iss 3 August 2010
    - Mobility Aids:- Vol 6 Iss 2 June 2011