

The role of advance care planning in end-of-life care for residents of aged care facilities

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Advance Care Planning, Advance Care Directive, nursing homes, residential aged care facilities, end-of-life, dying with dignity

ABSTRACT

Objective

This report will present the case of an elderly woman with rapidly declining health admitted to hospital from a nursing home. It will discuss benefits of advance care planning for residents of aged care facilities who have expressed opinions/wishes regarding their end-of-life care, and identify barriers, varying legal status, the need for documentation of discussion outcomes specifying residents' wishes, and the importance of education and expert support for nursing staff.

Setting

Nursing home and acute tertiary referral hospital.

Subject

Female resident of a nursing home, aged 97 years, with acute onset of abdominal pain and multiple co-morbidities.

Primary Argument

The majority of nursing home residents do not have advance care planning initiated, nor is this routinely raised by nursing staff. While wishes may be discussed with family, they may not be fully respected if undocumented. Acutely ill residents are frequently hospitalised, especially when death is imminent, and often die alone in unfamiliar surroundings, tended by strangers. Many of these admissions could be avoided with Advance Care Planning, as could the resultant medical interventions which may cause the resident acute pain and discomfort.

Conclusion

Advance Care Planning can lead to avoidance of non-essential hospital transfers and their inherent risks and is likely to facilitate a dignified, peaceful death in familiar surroundings for nursing home residents, averting medical interventions which may cause needless pain and prolonged suffering.

INTRODUCTION

Advance care planning (ACP) is a means of enabling the difficult subject of end-of-life care to be openly discussed between loved ones and the healthcare team, whilst the person is still able to effectively communicate their wishes in relation to their future health care in the event of incapacitation through illness or accident (Sellars et al 2015; Amjad et al 2014; Boot and Wilson 2014; Thomas 2008; Shanley and Wall 2004). Both in Australia and globally, most residents of nursing homes are transported to acute care facilities when their health declines rapidly and/or there is reasonable concern that death may be imminent (Gardhouse et al 2014; Caplan and Meller 2010). The availability of, and participation in, ACP may assist in preventing non-essential transfers of the resident from their residential aged care facility (RACF) to the emergency department (ED) of the nearest hospital (Reymond et al 2011). It is not the aim of the ACP to prevent transfers to hospital altogether, but rather to reduce the non-beneficial transfers and resultant complications which may be avoided by keeping the resident at their RACF (Van Gaal et al 2014; Caplan et al 2006; Shanley and Wall 2004). It is common for critically ill people to be sent to ED, despite evidence that those who avoided hospital transfers have fewer diagnoses of increased confusion or delirium (McCloskey 2011; Bezzina 2009; Caplan et al 2006).

LITERATURE REVIEW

Every competent adult has the right to consent to and to refuse medical treatment. This right is the fundamental basis of advance care planning (Advance Care Planning 2015).

The importance of ACP and ongoing communication between older persons, their families and healthcare professionals is progressively becoming recognised (Sellars et al 2015; Amjad et al 2014; Baughman et al 2014; in der Schmitte et al 2014; Stone et al 2013; Storey and Sherwen 2013) especially in Australia (Bird 2014). However, evidence persists that initiating ACP discussions with residents of RACFs remains difficult for staff (Boot and Wilson 2014; Dempsey 2014; Schubart et al 2014; Robinson et al 2013; Stone et al 2013). Notwithstanding the recognition that ACP is integral to person-centred care, a significant proportion of older persons do not have this in place (Schubart et al 2014; Boerner et al 2013; Rhee et al 2012). A number of barriers to the implementation of ACP have been identified, starting with, from the patient's perspective, a lack of knowledge, limited time if they are critically ill, emotional responses, cultural background, and denial of mortality. From a health professional's perspective, again, lack of knowledge is a factor, together with ambiguity regarding its processes (Sellars et al 2015; Boddy et al 2013). There are systemic barriers relating to the different requirements of each State or Territory as there is no uniform legislation and registry, nor is there definition of roles and responsibilities for those involved in the provision of care. There are also procedural issues, especially in the area of assessment of capacity which Boddy et al (2013) have identified in Australia as a medically-based decision. Some practitioners consider there is uncertainty regarding the stage at which capacity is lost and may not be aware of the procedure for determining absence of capacity.

ACP has its roots in the ethical principal of autonomy, in particular, the tenet of informed consent as established in the landmark 1914 court case, *Schloendorff v Society of New York Hospital*. In his widely quoted judgment for this case, Justice Cardozo ruled that competent adults were entitled to sole control regarding their own bodies. This decision has since been followed in Australian courts under Common Law to uphold the rights of persons to determine consent or refusal for medical treatment including in circumstances where death is the likely outcome (Advance Care Planning 2015). In 2009 a New South Wales judge ruled that compliance with advance care directives is appropriate, especially when the person is competent at the time of making such directive, was not unduly influenced, has not changed their mind, and met the existing medical circumstances (New South Wales Supreme Court 2009).

Whilst Common Law is well-defined, legislation has also been passed by State and Territory governments reiterating a person's rights in relation to medical treatment, or the refusal thereof; and all States/Territories, with the exception of Tasmania, legally recognise ACDs and the right to refuse treatment. However, consistency is lacking in policies and laws which support ACP. Indeed, the National Framework for Advance Care Planning (National Advance Care Directives Working Group 2011) identified multiple issues including disparities in terminology, inconsistent legislation, and restrictions on enacting advance care directives.

The need for ACP and its effective communication becomes apparent when an individual who is acutely ill develops physical and/or cognitive deterioration, and is incapable of accepting or declining medical interventions (Scandrett et al 2014; Boerner et al 2013; Dempsey 2013). ACP enables an individual to stipulate what their wishes are for future medical care should they be rendered incapable of making such decisions and, moreover, reduces the worrisome obligation on loved ones to function as proxy decision makers (Amjad et al 2014; Boot and Wilson 2014; Brinkman-Stoppelenburg et al 2014; Dempsey 2014; De Vleminck et al 2014; Boddy et al 2013; Jeong et al 2007). The implementation of ACDs is proven to reduce over-treatment when death is approaching, being consistent with the person's preferences and increasing satisfaction with the end-of-life care from both the family's and the person's points of view, thereby moderating stress (Sellars 2015). There is also evidence that initiation of ACP discussions has led to a decrease in depressive symptoms, especially in the early stages of dementia (Hilgeman et al 2014).

ACDs have also reduced the number of inappropriate hospital presentations and subsequent admissions for residents of RACFs (Sellars et al 2015; Boddy et al 2013; Silvester et al 2013; Stone et al 2013). This is an important reason for their use, as RACF residents may encounter complicating factors in the ED, such as unfamiliar doctors who do not know their history, and rapid health assessments which may compromise their complex needs, especially if they are unable to communicate effectively or are cognitively impaired (Arendts et al 2012). Those who are admitted to a ward face the increased possibility of adverse outcomes, including falls, pressure injuries, delirium, incontinence, and mortality (Renjel and Eeles 2014; Van Gaal et al 2014; Doran et al 2013; Arendts et al 2012; Ashcraft and Champion 2012; Lamb et al 2011; Codde et al 2010). Approximately half of RACF residents who present to the ED will be admitted to a ward, and 75% of those admitted will die by the fifth day (Ashcraft and Owen 2014).

CASE REPORT

Background

The aged care rapid response team (ARRT) received a telephone call from a registered nurse (RN) at an RACF who advised that a 97 year old female resident (Mrs K) had developed acute onset abdominal pain overnight with vomiting and nausea. Mrs K had informed the staff that she had felt some abdominal discomfort the previous evening, but in the morning had awakened with severe pain, despite taking her regularly prescribed analgesia. The RN had contacted Mrs K's general practitioner who directed her to administer an enema, which was done with little effect. As the day progressed, Mrs K's condition worsened, she was uncharacteristically drowsy, and her abdomen was distended, firm and painful to touch. Mrs K had recently been prescribed diclofenac, which, when combined with her already prescribed aspirin, may interact and could cause gastric bleeding. Mrs K had no written end-of-life care pathway or advance care directive (ACD) in place, so the RN was advised to contact Mrs K's daughter, Anne, and have Mrs K transferred to the ED as her condition could be very serious and required immediate investigation.

Diagnosis

A diagnosis of a perforated peptic ulcer was made, and Mrs K was admitted to a ward for treatment.

Health history

Mrs K had an extensive medical history including surgical procedures and hospital stays. She was cognitively intact and aware of the invasive procedures she could face if hospitalised again.

Plan

The admitting medical officer documented a plan which included investigative procedures, insertion of an indwelling urinary catheter, intravenous fluids, and nil oral intake.

Management and treatment

On admission, it was documented in the Multidisciplinary Assessment Form by the medical officer, in capital letters and underlined:

NO CPR, NOT FOR RESUS, NO ICU, NO INTUBATION, NO SURGERY, NO IVABS, D/W DAUGHTER

Mrs K was accepted under the care of the gastroenterology team and transferred to a ward where it was subsequently decided, after consultation with Anne, that she would receive palliative care.

Despite this, her medications were then varied considerably, including the introduction of intravenous antibiotics and the abrupt cessation of opiate analgesia, an anti-inflammatory, and a sedative. This caused her acute discomfort, nausea, vomiting, and diarrhoea which necessitated regular administration of an anti-emetic. In fact, ongoing administration of those ceased medications may have benefitted Mrs K the most. Her urine output dropped to 5-10mL/hour, a clear indication of potential kidney failure, however her treatment continued unchanged. Anne was not aware until the third day that Mrs K was receiving intravenous antibiotics, and advised medical staff that this was in direct contravention of the agreed treatment plan. The intravenous antibiotics were ceased and, when Anne made the observation that her mother was exhibiting signs of strong pain, subcutaneous morphine 2.5-7.5mg was prescribed as needed every two hours. Mrs K's intravenous fluid was reduced to 40mL per hour.

Anne consented to be interviewed for this report in relation to the care given to her mother. She advised that she knew her mother was not going to improve, and had wondered why her mother was prescribed intravenous antibiotics when recovery was so unlikely, given her obvious deterioration, and further, that within two days of hospitalisation her mother's condition had deteriorated to such an extent that she did not recognise her daughter and was no longer able to communicate.

When questioned about ACP, Anne stated that she knew nothing about it and that this subject had not been introduced by RACF staff nor her mother's GP. When given a brief overview of the purpose of ACP, Anne recalled a recent conversation during which her mother said:

"I've had a good life – when my time comes, I'm ready to go. Don't stick me full of needles and tubes. Don't hang on to me – I think I'd hate that. Let me go quick, in my own bed, with you holding my hand."

Anne enquired if that constituted advance care planning and was advised that it did, albeit informal and undocumented. It is clear from that statement that Mrs K would not have wanted the treatment she received in the hospital.

Outcome

Mrs K's condition continued to deteriorate over the course of her hospitalisation. Blood tests revealed multiple deranged results which worsened over three days, indicating excessive intravenous intake, renal failure, and infection. She became increasingly drowsy and delirious, and on the morning of day four, during early morning ward rounds at 0520hrs, she was found with no discernible signs of life. The cause of death was noted as 'perforated viscus'.

DISCUSSION

In the past decade, hospitalisation rates for men and women over the age of 85 have increased by 48% and 35% respectively (Swerissen and Duckett 2014). It is not at all uncommon for residents of RACFs to be transferred to hospital for many reasons, including diagnostic testing, acute illness, falls, and traumatic wound care (Van Gaal et al 2014; Shanley et al 2011). Often residents, are transferred when they are acutely ill and/or death may be imminent (Gardhouse et al 2014), which removes their privilege to die peacefully in a place of their choosing.

As residents of RACFs are usually frailer than their community counterparts, it is not surprising that they present more frequently to hospital (Wysocki et al 2014; Jayasinghe et al 2007). Due to their raised levels of morbidity, their risk of being admitted and dying during their admission is increased (Ingarfield et al 2009). Discussion of end-of-life care should therefore be considered an integral aspect of RACF care, which would entail offering residents, their families, and significant others the option of discussing views and preferences for care should a critical event occur (Dempsey 2014; De Vleminck et al 2014; Allen et al 2003). The outcome of these discussions can then be clearly documented (Bird 2014; De Vleminck et al 2014; Robinson et al 2013).

Although it has been shown that older persons residing in RACFs who discuss their wishes with family members are more likely to have documented ACP in place than those in the community (Allen et al 2003), this did not occur in this instance, most likely due to a combination of Anne's lack of understanding what ACP constitutes and the facility's failure to initiate a conversation in this regard. It would appear that this would have been an ideal situation for discussion and implementation of ACP in the RACF, particularly as Mrs K had openly discussed her wishes with Anne. It may well have precluded Mrs K's transfer to hospital, where she became delirious, a development not uncommon in hospitalised older persons (Renjel and Eeles 2014). In fact, evidence substantiates the benefits of persons remaining in their place of residence, citing familiarity, comfort, and continuity of care (Evans 2011; Allen et al 2003).

In this particular case, Mrs K's acute onset of symptoms did require investigation and diagnosis, so ACP may not have prevented her transfer to hospital. However, documentation of her wishes would have avoided the abrupt cessation of opiate analgesia and a sedative and the initiation of a strong intravenous antibiotic regime, which caused severe nausea and vomiting and significantly increased Mrs K's level of discomfort in her last days. Persons who do not have documented ACP may be given unwanted medical treatment, and indeed are often over treated (Boerner et al 2013), which appears to be the case here. Further, had Mrs K specified a desire not to be transferred to hospital in the event of an acute decline in her health status, this in fact may have been honoured. It was not known to Anne or the RACF that Mrs K's express wish to die in her own bed constituted a desire not to be transferred from her place of residence. Research has identified a statistically significant difference in the proportion of older persons with ACP who have died in hospital compared with those who remained in their place of residence, finding the former much lower (Bischoff et al 2013).

ACP has been proven to lead to a reduction in emergency presentations and subsequent hospital admissions (Boddy et al 2013; Stone et al 2013), and may also guarantee the provision of care as specified by the resident (Brinkman-Stoppelenburg et al 2014; Shaw et al 2010; The Gold Standards Framework 2010; Badger et al 2007). The crucial aspect of planning for end-of-life care should not be assigned to fate by its omission (Evans 2011) but should be a customary feature of care, clarifying health care needs of the resident (Baughman et al 2014; The Gold Standards Framework 2011). This is important when residents are no longer able to speak for themselves, thereby ensuring, where possible, a dignified and peaceful death (Phillips et al 2011). But the issue of raising ACP and its subsequent documentation is a difficult one, particularly in RACFs where new residents and their families are often not ready to consider or discuss such options. Language barriers

may also be a factor, together with cultural taboos (Boot and Wilson 2014; Dempsey 2014; Thomas 2008; Shanley and Wall 2004). However, lack of knowledge about ACP has been identified as the foremost barrier to its implementation in RACFs (Boddy et al 2013; Jeong et al 2007). Jeong et al (2007) suggested that a designated expert in ACP would assist in providing guidance in RACFs. At the time of writing, in the Local Health District where Mrs K resided, such an expert is not employed. However, the ARRT regularly raise the issue of ACP with RACF residents they visit.

ACP achieves success when a multi-system method is implemented, including involvement and support from the community, development of administrative policies and procedures, staff education, and appropriate documentation practices (Sellars et al 2015). In its Interim Report the Clinical Excellence Commission (CEC) (2008) recommends the use of prioritised approaches to facilitate practice change. This may well improve ability of RACF staff to initiate discussions with the resident and family. One such approach is the use of a forcing function, a feature that precludes completion of an action unless a specific task is first performed (Patient Safety Network 2015); for example, completion of the admission forms cannot take place until a section on ACP is filled out.

Had Mrs K not clearly made her wishes known to her daughter, she may have been subjected to even more prolonged treatment which may have extended her life with pain and suffering. This would have been in contravention of her wishes since she was no longer capable of making decisions. If ACP had been broached by the RACF staff, Mrs K's wishes may have been documented, and subsequently followed.

CONCLUSION

Mrs K died alone in hospital, which was not her wish. The circumstances of her illness would have been ideal for the implementation and documentation of ACP. According to her daughter, Mrs K had no difficulty discussing her end-of-life care wishes with her and, presumably, would have been amenable to discussions with the RACF staff had the issue been raised. Mrs K's decisions could have been documented in an Advance Care Directive which may have avoided the active, invasive medical interventions that exacerbated her acute discomfort in her last days.

This case study highlights the fact that ACP is not routinely discussed with residents upon their entry to RACFs, and that this omission may, in consequence, have detrimental effects on the quality of life, and death, of the residents. The barriers to such discussions are becoming clear, and it would be beneficial to address these by investigating solutions to the obstacles, and requirements for further education and support of staff in RACFs in relation to ACP, its discussion, documentation, and implementation.

RECOMMENDATIONS

Generally, alignment between the States/Territories' requirements and documentation may resolve discrepancies. This, together with ready access to standardised procedural information and documents from a central source, is likely to reduce the confusion and uncertainty surrounding ACP expressed by professionals and patients alike. The formation of a working party to address these issues is warranted.

A systematic method for the practice of ACP, particularly in RACFs, is required for person-centred care to ensure the residents' wishes are known and respected. This should include education for staff on initiating discussions with residents and their families, and the subsequent documentation of decisions reached. Furthermore, the development and implementation of a standardised form, including a forcing function, across these facilities would enhance this process. Support from professionals experienced in the practice of ACP, for example a clinical nurse consultant, may prove useful in initiating and reinforcing these practices. The feasibility of a designated expert employed in the community sector to regularly visit RACFs should therefore be investigated.

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