The renal memorial service: an important component of renal supportive care

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Abstract

To assist in supporting the loved ones, health care workers and surviving renal patients in their grieving process, as well as celebrating the lives of patients who have died, a renal memorial service (RMS) was initiated at our hospital in 2011. This paper describes the development, implementation and evaluation of the RMS.

The RMS has been conducted twice and formally evaluated. The evaluation identified that the service provided relatives and friends with an opportunity to connect with and thank staff who provided care for their loved ones. Of interest is that while the service was acknowledged as beneficial by nursing staff, attendance was poor and requires further investigation. As the RMS has been identified by relatives and loved ones as beneficial, it will remain as an important component of the comprehensive renal supportive care at our hospital.

Keywords

Supportive care, renal palliative care, renal memorial service, dialysis deaths.

Introduction

The relationships that develop between renal health care workers and their patients and families are unique in that they usually develop over an extended period of time. Furthermore, when patients require renal replacement therapies they are then involved with a number of health care workers at regular follow-up clinics or dialysis sessions. Indeed, dialysis nurses may see the same patient and family when they attend the dialysis centre three times a week for many years. For this reason, the death of a dialysis or transplant patient touches not only the family and friends but also the health care workers and the patients they have bonded with over the length of their treatment.

The number of people receiving dialysis across Australia as at 31 December 2010 was 10,590. The life expectancy of a patient receiving dialysis is dependent on his/her age and comorbidities and the number of deaths for this patient group in 2010 was 1401 (ANZDATA, 2011). Of the 1401 deaths among dialysis-dependent patients in 2010, 35% were due to withdrawal from treatment, 43% were due to cardiovascular causes, 11% infection and 6% from malignancy (ANZDATA, 2011). The statistics on patient deaths for our renal service are comparable to national statistics with 37 deaths in 2011, which is a 15% death rate and comparable to the ANZDATA 2011 report for Australia.

Our renal department has a comprehensive supportive care service which provides support and management for patients with advanced chronic kidney disease and their families (Josland *et al.*, 2012). A major aspect of this support is the provision of bereavement services for loved ones, other patients and staff after the death of a patient. The social worker is pivotal in this role and provides debriefing with the patients who developed a relationship with the deceased patient; debriefing support for staff and also contacts the family and becomes the bridge between the unit and the family.

To enhance the bereavement service our dedicated renal supportive care team implemented the annual renal memorial service (RMS) in 2011 to celebrate the lives of patients who have died and to support the loved ones and health care workers in their grieving process. This paper describes the development and implementation of the RMS. Evaluation findings will be presented, particularly the positive feedback from attendees. Only a small number of staff have attended the RMS and the reasons for this as well as the perceived bereavement needs of staff will be discussed.

Literature

Bereavement is the state of having suffered the death of

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someone significant (Young, 2009). Although there are many grief theories, the individual reacts to death and works through the grief process in his/her own way (Brown & Wood, 2009). The majority of bereaved people manage their grief with the support of family, friends and neighbours and only a small proportion (10–20%) experience prolonged grief disorder, benefiting from professional intervention (Aoun *et al.*, 2012).

A study conducted in a hospice in the USA found that the families of those who died from renal failure were one of the groups who requested additional bereavement services. This additional support included regular phone follow-up and home visits and attendance at a memorial service. The author suggested that patients with renal failure had a shorter length of hospice stay indicating greater unmet needs (Jones, 2010). This study supports the significant need for bereavement services for the families of patients who die from renal failure.

Unlike hospices, renal units do not usually have the resources or the expertise to provide bereavement services (Brown *et al.*, 2007, p. 274). Activities which may be undertaken to support the bereaved include notices in the waiting room, posting obituaries, placement of a ritual flower arrangement and card by the nursing station (Poppel *et al.*, 2003), condolence cards or letters of sympathy, bereavement information leaflets, attendance at funerals and conducting memorial services for those who have died within the past year (Brown *et al.*, 2007, p. 274). The continuing emotional support from valued and trusted professionals who were involved in the care of the deceased rather than a bereavement service is more appropriate and beneficial for the bereaved (Brown *et al.*, 2007, p. 274; Holley, 2005).

A common component of many bereavement services is a memorial service to support people who have lost a loved one (Mather *et al.*, 2008). Memorial services are more often held as part of a hospice bereavement service but memorial services have been conducted for families of patients who have died in a hospital setting (Rawlings & Glynn, 2002).

One such example is the planning, implementation and evaluation of a memorial service by nursing staff for relatives of patients who died in an intensive care unit in the United Kingdom (Platt, 2004). The memorial service evaluation revealed that the participants were happy with the memorial service and evaluation was established as a critical component for future services (Platt, 2004).

The literature suggests that there are some renal services which have conducted memorial services (Ormandy, 1998; Poppel *et al.*, 2003; Nulsen & Noble, 2009; Chambers *et al.*, 2010). Poppel *et al.* (2003) describe two components of a bereavement support service for patients within a renal service. Firstly, the acknowledgement of deaths so that staff and other patients are aware of the death of a patient and, secondly, initiating annual RMSs, modelled after those that are commonly held in hospices.

Ormandy (1998) describes the way renal unit nurses offered support to bereaved relatives by organising a memorial service for relatives of patients who had died over the previous 12 months. The structure of the service came from a variety of remembrance services and was an ideal opportunity to provide support and comfort to bereaved relatives, reinforcing the idea that patients, relatives and friends are valued by those who care for them. Nulsen and Noble (2009) examined the role of a service of remembrance in meeting the needs of bereaved families, friends and staff. It was identified that their memorial service was invaluable in assisting relatives in their grieving but it was found that the majority of the health care staff did not attend. The reasons for this were not clear and warranted further investigation into nurses' responses to death when they work in areas of high patient mortality.

Cohen (2002) on behalf of the Renal Palliative Care Institute developed the *Service of Remembrance Manual* to assist renal units. The service of remembrance is described as an annual non-denominational program designed to remember the patients who have died during the year. It unites members of the renal community: family members, doctors, nurses, social workers, dietitians, technicians, van drivers, fellow patients and others impacted by the death. The service of remembrance is a collaborative effort to meet the bereavement needs of all. Cohen suggests that remembrance can be simple or elaborate, it can be confined to one unit or area or cover a broader area. It should be designed in whatever format thought to be appropriate for the needs of the bereaved community. Cohen (2002) emphasises that initiation of the service of remembrance takes diligence, planning and must be sensitive to the needs of the bereaved and the different cultures.

One successful service of remembrance that is sensitive to the needs of the bereaved is that conducted annually in Australia by DonateLife. The service provides a forum for acknowledgement of and gratitude to organ donors and their families (DonateLife, 2012). Anecdotally it is thought that other Australian renal units have conducted memorial services but there is no evidence in the literature.

For our large renal services the introduction of the RMS was a natural progression to the provision of holistic, comprehensive supportive care for our patients, families and their carers.

The RMS

The renal social worker is charged with taking the organisational lead for the RMS with oversight and assistance from other members of the Renal Supportive Care Committee. Our first RMS was held in April 2011.

The first step in planning the RMS is to source and book a suitable venue well in advance. We use our hospital function area, which is located away from the main hospital campus and has coffee/tea-making facilities. The venue is easily accessed by public transport and is situated next to the hospital car park. It is important for us to have a secure and safe venue as the RMS is held in the evening to cater to the needs of working family members.

Invitations to the RMS are sent to the next of kin of patients who have died during the previous two years. The renal

department staff maintain online comprehensive patient data and "real time" information including patient deaths is recorded into the system. As meticulous record keeping is encouraged it is possible to run a report of deaths for a given period of time. It is therefore not an arduous task to identify the patients who have died over the previous two years and the address of their next of kin. The next of kin are asked to invite any other relatives or friends they would like to attend and to RSVP the number of attendees to the social work department. A map of the venue location is enclosed with the invitation.

Given the strong relationships that develop between patients who undergo dialysis, current patients are notified of the impending RMS by posters on the noticeboards on the dialysis units and in clinics. Patients are also alerted by the social worker personally when visiting the unit. Staff are informed of the upcoming RMS in ward meetings and via email. A general notice is placed in the local newspaper two weeks prior to the service.

A major consideration in our planning is the potential audience for the RMS. People living in the catchment area for our hospital and community service are a culturally and linguistically diverse group. Many do not speak English or their command of English is poor. In addition, patients and families are from diverse religious backgrounds and for this reason the service is designed to be non-denominational. Assistance is always sought from Pastoral Care at our affiliated palliative care hospice when developing the course of proceedings for the RMS. Their expertise in conducting regular memorial services was invaluable especially when suggesting a theme and program. In 2011 the RMS theme was autumn and in 2012 the theme was water and tranquillity. The short, 30-minute service includes music, candle lighting and poetry reading. Following the RMS the attendees are invited to remain for light refreshments. Some families bring food to share.

Evaluation/feedback

Attendees at the RMS were given an evaluation form to complete and return to the renal social worker. Informal feedback and the formal evaluation surveys revealed that the RMS was a positive experience for the families who attended. This is evidenced by the following comments:

> *Our sister lives in America and couldn't attend the memorial service. She also couldn't come for J's funeral because she was sick. We keep the memory of J alive through pictures, videos, and mementos that we share with one another. I know our sister will really appreciate being able to see the video/pictures of the memorial service, so she can feel a bit more like she was there.* (RMS attendee, 2012)

> *Mum said after the service that it [the service] has helped her in getting some closure [in losing dad]. It's Mum's 80th birthday tomorrow. I think we were more apprehensive about coming to the service than Mum was. Knowing Mum is finding closure it is helping us with our own closure in turn, and we know we can worry less about Mum.* (RMS attendee, 2012)

One attendee expressed his wish to visit the dialysis unit to thank the staff. He was hesitant to go back into the hospital environment because he felt he was "not ready". As the RMS was held away from the hospital, he felt comfortable attending, in the hope that he would be able to speak to and thank the staff.

> *I have wanted to find a way to communicate my appreciation to the doctors and nurses for the care they took of my wife, but I haven't been able to bring myself to go back into the dialysis unit yet. I feel relieved that I have been able to give my thanks in person to the staff who attended this memorial service.* (RMS attendee, 2012)

Discussion

To date, two annual services have been held with a total of 60 people attending. Families and friends comprise most of the attendees with only a small number of current patients and staff representatives at each service.

As highlighted in the evaluation surveys, the RMS has been well received by families and friends who attended especially in regard to the venue and the proceedings. The families and friends saw the RMS as an ideal opportunity to share their stories with other families with similar experiences and to reconnect with health care providers who had long been associated with the care of their loved ones.

There are a number of people who declined the invitation to attend the RMS. Families and friends may feel that they have moved on from the initial shock of the death of their loved one and do not wish to face the strong emotions evoked by a memorial service (Rawlings & Glynn, 2002). In addition, the majority of bereaved people manage their grief in their own way with support from close families and friends (Aoun *et al.*, 2012). For these reasons there has been no formal follow-up with people who chose not to attend.

Although staff have expressed their support for the RMS only a small number have attended. Focus groups with nurses held during RMS feedback sessions revealed that there were a number of reasons why they did not attend. Some felt that they would attend if the timing was more appropriate to their shifts. The RMS is held at night to allow for family to attend following work commitments. Dialysis nurses would prefer if the RMS is held during the day to allow them to attend during their shift rather than waiting or returning to the hospital at night. These reasons for poor staff attendance support the findings of Nulsen and Noble (2009).

The literature on memorial services suggests it is a way of providing closure for nurses when contact with the patients and their families have abruptly ceased through death (Poppel *et al.* 2003) but some of our nurses stated that they had different ways of handling the loss of a patient and an RMS was not of benefit to them.

Nurses present at focus groups suggested that the most important way of coping with difficult incidents, including the death of a patient, was through the support they received from

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References: 1. Ferinject® Product Information.
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colleagues. They felt that a conversation with colleagues either formally in a debriefing meeting or informally in the tearoom, was reassurance to themselves that they did a good job and their contribution was the best they could do. They got comfort from reminding themselves that the patient was not suffering any more.

Individual nurse comments during follow-up focus groups included:

> *I have always been more involved in the journey than some family members and I do not need to attend a memorial service because I have already paid my respects and moved on to the usual work of caring for the rest of my patients.* (Focus group participant, 2012)

> *I think a memorial service is great for family and friends but I would not want to attend. I like to keep my work life and personal life separate. We [nurses] have a life out of work and often have to face our own grief at times.* (Focus group participant, 2012)

Implications for future research

Future research is planned to explore haemodialysis nurses' perceptions of the death of a dialysis patient and the ways of coping with an aim to develop bereavement services to suit their needs. A review of the literature on this topic has found that studies carried out with renal nurses in Greece (Zyga *et al.*, 2011) and in Spain (Ho *et* al., 2010) suggest that the introduction of an education program for nurses would assist them in the care of the dying patient. There are no studies which specifically focus on dialysis nurses' attitudes and bereavement needs after the death of a patient and no studies conducted on this topic in the Australian context.

The social workers are collaborating to develop hospital-wide bereavement guidelines and the work conducted in our unit will help inform these guidelines and help ensure the ongoing success of the RMS.

Conclusion

The organisation of an RMS requires thorough planning and support from the health care team and in this case the advice from pastoral care experts. The RMS provides the opportunity to support and comfort bereaved relatives, strengthening the concept that patients, relatives and friends are valued by the health care workers who care for them.

There is little understanding of the perceptions of dialysis nurses and their ways of coping when a patient has died. This topic needs further work and will be addressed in a formal research study. The comfort the relatives expressed from meeting with staff has been conveyed to the nurses and this might encourage them to attend in the future.

As the RMS has been well evaluated by families and friends, the service will continue to be conducted yearly.

References

Aoun, S., Breen, L., O'Connor, M., Rumbold, B. & Nordstrom C. (2012) A public health approach to bereavement support services in palliative care. *ANZ Journal of Public Health*, *36*(1), 14–16.

Australia and New Zealand Dialysis & Transplant Registry. The 34th Annual ANZDATA Report. http://www.anzdata.org.au/v1/annual_reports_download.html

Brown C. & Wood A. (2009) Oncology nurses' grief: a literature review. *Clinical Journal of Oncology Nursing, 13*(6) 625–627.

Brown, E., Chambers, E. J., & Eggeling C. (2007) *End of Life Care in Nephrology.* New York: Oxford University Press.

Chambers, E. J., Brown E., & Germain M. (2010) *Supportive Care for the Renal Patient. 2nd Ed.* New York: Oxford University Press.

Cohen L. M. for The Renal Palliative Care Institute. (2002). *The RPCI Memorial Service Manual.* RPCI: Massachusetts.

DonateLife http://www.donatelife.gov.au/the-network/donatelife-in-nsw/events/details/259-annual-service-of-remembrance-and-reflection-2012

Ho, T. M., Barbero, E., Hidalgo, C. & Camps C. (2010) Spanish nephrology nurses' views and attitudes towards caring for dying patients. *Journal of Renal Care, 36*(1), *2–8.*

Holley J. (2005) Palliative care in end-stage renal disease: focus on advance care planning, hospice referral, and bereavement. *Seminars in Dialysis, 18*(2), 154–156.

Jones B. (2010) Hospice disease types which indicate a greater need for bereavement counselling**.** *American Journal of Hospice and Palliative Medicine, 27*(3), 187–190.

Josland, E., Brennan, F., Anastasiou, A. & Brown M. A. (2012) Developing and sustaining a renal supportive care service for people with end stage kidney disease. *Renal Society of Australasia Journal, 8*(1) 12–18.

Mather, M. A., Good, P. D., Cavenagh, J. D & Ravenscroft P. J. (2008) Survey of bereavement support provided by Australian palliative care services. *Medical Journal of Australia, 188*(4) 228–30.

Nulsen, R. S. & Noble H. (2009) A memorial service to remember renal patients who have died. *End of Life Care, 3*(2) 56–62.

Ormandy P. (1998) A memorial service for renal patients. *EDTNA ERCA Journal*, *24*(3) 22–4.

Platt J. (2004) The planning, organising and delivery of a memorial service in critical care. *Nursing in Critical Care, 9*(5) 222–229.

Poppel, D. M., Cohen, L. M. & Germain M. J. (2003) The Renal Palliative Care Initiative. *Journal of Palliative Medicine, 6*(2), 321–326.

Rawlings, D. & Glynn T. (2002) The development of a palliative care-led memorial service in an acute hospital setting. *International Journal of Palliative Nursing, 8*(1) 40–7.

Young S. (2009) Rethinking and integrating nephrology palliative care: a nephrology nursing perspective. *The CANNT Journal*, *19*(1), 36–44.

Zyga, S., Malliarou, M., Lavdaniti, M., Athanasopoulou, M. & Sarafis P. (2011) Greek renal nurses' attitudes toward death. *Journal of Renal Care, 37*(2) 100–107.