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Submission by RDNS
to
Senate Standing Committee on Community Affairs

Inquiry into Palliative Care in Australia

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Submission to the Senate Community Affairs Committee's inquiry into *Palliative Care in Australia*

When we think about how we might like to die, most of us opt for going comfortably and quietly in our beds, in our homes (if possible) supported by trusted family, friends and carers. However, sadly for all too many Australians, the place and support is quite different.

The Senate Community Affairs Committee's inquiry into Palliative Care in Australia is timely and welcome. The greater the debate and discussion on how and where Australians can die with dignity, supported and nurtured by those that care for them, the greater the likelihood the broader community will feel able to support each other achieve the type of death desired by each individual. Royal District Nursing Service Limited (RDNS) A.C.N 052 188 717 welcomes the opportunity to respond to the Senate Community Affairs Committee Inquiry into Palliative Care in Australia and contribute to this important debate.

ABOUT RDNS

Royal District Nursing Service Limited (RDNS) is the largest and oldest provider of home nursing and healthcare in Australia, with services in Victoria, Tasmania, New South Wales and New Zealand. On any given day RDNS has over 9,000 clients in admitted status, and in 2010-11 Palliative Care directly attributed 1,704 admissions or 5.8% of the total 19,600 admissions recorded in Victoria and New South Wales. As a service that provides a flexible, mobile and responsive workforce we support that, wherever possible, care and support should be provided in the setting of choice for the client. This applies across all types of services we provide, but particularly when responding to and supporting clients who require palliative care. RDNS has service agreements with seven Victorian Government-funded specialist palliative care services, and provides services on behalf of each of these seven agencies in the various areas of Melbourne, ranging from all general and specialist community-based nursing care through to providing only after-hours emergency telephone advice. This support is achieved through our nurse led 24-hour Customer Service Centre – a single point of contact that facilitates communication with clients, carers, health professionals, referrers and staff around the clock.

As a significant contributor to the community care component of palliative care service provision, RDNS makes comment on the following key areas:

- Equity of access
- General versus specialist palliative care
- Workforce issues
- System support structures
- Carer support and education
- Advance Care Planning
- After Hours Services

Equity of Access

The need for palliation goes beyond cancer care. Although cancer care remains a major component of palliative care, RDNS has experienced the need for palliative care in many other clinical areas. Most notably, RDNS provides a dedicated district nursing HIV/AIDS service in Melbourne. The service system and funding must look beyond the traditional diagnoses associated with palliative care to consider all those which fit the principles of the palliative approach.

As with other areas of healthcare, innovative service delivery models should be pursued to ensure adequate support is available at all times to clients, carers and staff, particularly where distance adds to the challenge. The utilisation of assistive technology can prove particularly valuable when dealing with remoteness. The ICT capacity available in facilities such as RDNS' Customer Service Centre can contribute significantly to reducing the disadvantage associated with remoteness. This view is supported by Palliative Care Australia's observation in December 2011 that "eHealth (is) vital for Aged and Palliative Care Reform."[1]

Recommendations

1. The availability of palliative care services should be needs-based, not diagnosis-based.
2. Innovative care models should be pursued, particularly utilisation of technology including video-conferencing to support the dying person, families and carers (both paid and informal).

General versus specialist care

RDNS believes quality end of life care requires an integrated mix of general and specialist interventions and agrees with Palliative Care Australia's assertion that, "a key element in providing quality needs-based end of life care is ensuring that those involved in the provision of end of life care, whether as primary or specialist palliative care providers, are equipped with the skills and resources to perform their roles effectively."[2]

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[1] Palliative Care Australia (2011) *eHealth Vital for Aged and Palliative Care Reform. Media release:* 19 December 2011

[2] Palliative Care Australia *Primary Health Care and End of Life* Position Statement. Retrieved March 2012

As a district nursing service, RDNS has significant experience of providing both general and specialist nursing care. The number of nurses with high-level knowledge and experience of the palliative approach, particularly of some of the highly technical requirements of end of life care, and the special psychosocial support required by clients, their carers and their families, is limited. It is therefore important to ensure that this scarce resource is best utilised. Much of the care provided to palliative care clients can and should be provided by generalist nurses with support available from a specialist nurse and following the care plan produced in collaboration with the specialist nurse and other health professionals.

RDNS utilises a model where our large team of generalist nurses have access to RDNS employed specialist palliative care nurses (Clinical Nurse Consultants), either immediately via telephone or by arranging a joint client visit, to assist them in providing general nursing care to palliative care clients. In addition, Victoria has multidisciplinary specialist palliative care services across the service system available for consultation and limited direct care delivery. This ensures that clients with the most complex needs are able to access the benefit of specialist support via their existing service arrangements.

Recommendation

3. Care provided to palliative care clients can, and should, be provided by generalist nurses with the right support (video-conferencing, telephone access to a range of specialists and participation in case conferencing).

Workforce issues

Many nurses are keen to pursue further professional development and qualifications if adequate support is available. However, there are two key impediments to this:

1) The financial impost of tertiary education costs, some of which can, and has been, assisted through scholarships and grants, and

2) The ability of employers to free key staff from their roles to attend education sessions and prepare assignments.

RDNS has previously provided assistance to its experienced nurses to progress to Nurse Practitioner level. Our experience with palliative care, as with other clinical areas, is that many senior nurses have not pursued this opportunity due to the extremely heavy academic workload required over several years. In addition, there is still limited knowledge in the community (including community-based pharmacists) of the role and legal scope of practice for Nurse Practitioners resulting in unnecessary and burdensome hurdles for the nurse practitioners to overcome on a weekly basis.

It is also important that exposure to palliative care occurs early in the education of health professionals. Therefore, RDNS supports all undergraduate courses for all health practitioners including education on Palliative Care.

PEPA (Program of Experience in the Palliative Approach) provides some less formal exposure and refresher courses in a supported environment for many health workers of various levels. Participants apparently appreciate the experience and knowledge these placements provide. The opportunity for staff to gain experience through PEPA ensures future capacity in the palliative care workforce.

The Palliative Care workforce is not immune to the same issues facing the healthcare industry more broadly, ie. the challenge of maintaining sufficient workforce in the face of increased demand through an ageing population and an ageing workforce. It is therefore vital that new and innovative ways of providing the right care by the right person are investigated. An example of workforce innovation that warrants further examinations is the greater use of the third tier worker supported by a robust clinical governance system and the worker mentored and paired with skilled registered nurses.

In addition to this notion of the 'right care by the right person', we must look at where it is possible for technology to assist or substitute effectively. Although there will always be a need for personal intervention, remote monitoring has been found to be an effective adjunct to face-to-face care. In light of the many workforce challenges, more funding to test assistive technology and remote monitoring in palliative care is required.

Dealing with the emotional impacts of providing end of life care and support to the palliative client, their families and their care network is skilled and challenging work. RDNS provides counselling and debriefing for staff, however, this is limited and can be difficult for them to access. The various current funding arrangements do not acknowledge the emotional support and ongoing education that staff require in order to continue to remain in palliative care. Key to sustaining the palliative care workforce into the future will be ensuring that staff are appropriately supported and developed so that they remain within this vitally important area of practice.

Recommendations

4. All undergraduate courses for all health practitioners should include education on Palliative Care .
5. Greater investment in developing assistive technology as an adjunct to face-to-face care.
6. Counselling and ongoing education is included in any funding arrangement specifically for staff, be they health professional or providing personal or domestic assistance.

System support structures

At a single agency level, RDNS provides a 24/7 support service for our staff where expert advice and support is available via telephone at any time. All nurses are also equipped with state-of-the-art mobile computer technology which allows them to access necessary information remotely from the point of care in real-time. This means that nurses have access to important reference material such as RDNS policies and procedures and external reference sources such as MIMS On-line at all times. Medication and other treatment orders can be received electronically, and communication to and from other members of the healthcare team is available to staff in real-time as well. Additionally, with some specialist palliative care service partners, RDNS nurses now have access to the partner organisation's PalCare system (patient admission system) via their mobile computers and the

Customer Service Centre. The three (3) principal benefits have been: firstly, to provide a greater after-hours coverage and support of palliative care clients; secondly, it has enabled palliative care clients to receive continuity of care as informed nurses can respond to client need after hours; and finally, the model enables a greater number of generalist nurses to be available to respond in a timely way to palliative care clients in need.

In Victoria, RDNS has participated in, and contributed to, the Palliative Care Consortia established regionally by the Victorian Government. This has provided greater opportunity to consider planning and funding on the basis of regional need. Of particular note, the Palliative Care Consortia are inclusive of Hospital, Hospice and Community-based care and have enabled the type of arrangements that have previously been described.

RDNS is of the view that the current development of the electronic health record should enable better access to health information by health and care practitioners similar to that currently employed by RDNS and participating Palliative Care Consortia in Victoria.

Recommendation

7. Palliative Care clients should be considered for preferential access to the electronic medical record as it is rolled out across the healthcare system.

Support for Carers

The role of carers is vital in palliative care, as it is in other areas of community-based care. Greater recognition of the role played by informal carers has occurred in recent years; Carers Victoria estimates that 70% of all care provided in the community is undertaken by informal, unpaid carers. Reports such as the recent ones produced by the Productivity Commission (*Caring for Older Australians* and *Disability Care and Support*) have highlighted the reducing availability of informal carers and this will impact significantly on care provision in the future. Within palliative care, it is essential that the role of carers is enhanced and supported further in four main areas:

- Improved access to respite care
- Enhanced grief and bereavement support
- Improved education and information for carers
- Psychosocial support

Caring for a family member once a palliative care approach is determined or end of life care is commenced is stressful for the family. Competing family demands, distance, financial pressures and anxiety about capacity to cope often come into play.

Providing education and effective support to family carers in this situation can do a lot to increase confidence to care for the palliative family member. For education to be successful, it needs to be provided when required and in a format that is acceptable to the person receiving the information and education. Health professionals need additional skills in order to be able to do this.

Recommendations

8. Carer education is crucial to developing their knowledge and confidence and should be appropriately funded and supported with a wide range of flexible materials.
9. Health professionals providing carer education need additional training and education in adult learning in order to be able to successfully support carers.

Equipment and supplies

Equipment is usually able to be accessed in a timely manner in Metropolitan areas. However, this is not true of rural areas as there can be limited providers and hospitals carry only small equipment stocks.

Frequently, pharmacies do not stock the drugs required for end of life care. This can result in either the palliative client experiencing delay of a day or so while the drugs are delivered from the importer to the pharmacy, or the client's family or care-giver is forced, under stressful circumstances, to contact multiple pharmacies to have a script filled. This is situation is exacerbated after-hours due to pharmacy operating hours.

Advance Care Planning

Advance care planning is important in meeting the needs of individuals at the end of life. Advance Care Planning, as practiced in some areas of Victoria, can provide significant reassurance to the client, the family or the informal care network that the wishes of the palliative care client will be understood, documented and followed. However to be done well, considerable training of staff is required and support, both in payment of related course fees and paid release from day-to-day responsibilities, is also necessary. National consistency in law and policy for Advance Care Directives would be beneficial. Complementing this should be a national community awareness program provided to ensure that all sectors of the community (including the healthcare community) are aware of the increasingly widespread use of Advance Care Plans.

Recommendation

10. RDNS supports national consistency in law, policy and training in Advance Care Planning.

After-hours services

Our experience as a 24/7 service tells us that in palliative care, provision of expert and timely clinical response is vital. If care and support is not resourced appropriately around the clock, all too often the outcome will be an otherwise avoidable presentation to a hospital. Such presentations place extra pressure on already stretched acute care facilities, but also undermine the client's desire to manage end of life care at home. Confidence that quality care and support is available around the clock reinforces the client's and carer's decision for end of life care at home, where appropriate.

Recommendation

11. RDNS believes greater investment in robust after-hours response systems can greatly enhance end of life care.

Summary of recommendations

1. The availability of palliative care services should be needs-based, not diagnosis-based.
2. Innovative care models should be pursued, particularly utilisation of technology including video-conferencing to support the dying person, families and carers (both paid and informal)
3. Care provided to palliative care clients can, and should be, provided by generalist nurses with the right support (video-conferencing, telephone access to a range of specialists and participation in case conferencing).
4. All undergraduate courses for all health practitioners should include education on Palliative Care.
5. Greater investment in developing assistive technology as an adjunct to face-to-face care.
6. Counselling and ongoing education is included in any funding arrangement specifically for staff, be they health professional or providing personal or domestic assistance.
7. Palliative Care clients should be considered for preferential access to the electronic medical record as it is rolled out across the healthcare system.
8. Carer education is crucial to developing their knowledge and confidence and should be appropriately funded and supported with a wide range of flexible materials.
9. Health professionals providing carer education need additional training.
10. RDNS supports national consistency in law, policy and training in Advance Care Planning.
11. RDNS believes greater investment in robust after-hours response systems can greatly enhance end of life care.