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Re: Caring For Older Australians-Productivity Commission Issues Paper

We offer contribution around some of the key areas outlined in the Issues Paper. Overall, research conducted at the Centre for Health Communication has shown:

1. The necessity of learning from patient and family experiences and involving patient and families in ongoing decision making.
2. The deficits in End of Life Care for Older Australians

In this regard we endorse the following documents:

- Guidelines for a Palliative Approach in Residential Aged Care [1]
- Health System Reform and Care at the End of Life-A Guidance Document [2]

In what follows we comment on specific issues:

1. Increasing Need for Psychogeriatric and Palliative care

There is substantial concurrence in the literature that Western healthcare systems are not addressing the needs of Older Australians towards the end of life. A recent Western Australia population based study confirmed the complexity of dying with chronic illness[3]. In a review of death certificates, only 22% had just one cause of death listed. It was also reported that a high proportion of people spent a significant amount of time transferring back and forth from hospital, and that a large proportion of carers expressed high levels of pain, suffering, and unmet concerns [3]. Given an ageing population, where the number of people living with a chronic or complex illness is predicted to increase, the need for further investigation of appropriate models of care is substantial.

Failure to acknowledge that patients are dying is notable in the literature. Studies highlight difficulties in diagnosing dying [4, 5] and even when recognised, poor prognosis is rarely communicated to patients and families[5-7]. Relief of pain and other symptoms is often inadequate and response to the psychosocial needs of patients and their families is poor, [8]. While most people die in institutions, hospitals are organised around the goal of cure, with

a focus on hospital efficiency, routines and tasks that concentrate on patients' expected recovery and elderly patients are often transferred back and forth from residential and aged care facilities to hospitals. These goals are inconsistent with the needs of the dying and their families [9]. With a focus on cure, investigations and medical interventions often continue right up to death [5, 10].

Specifically related to people with advanced dementia the literature highlights the ambivalence of recognition of dementia as a terminal illness having significant implications for care. In the final year of life symptoms of dementia are comparable to those of cancer [11]. Studies in the Australian context have highlighted poor recognition and treatment of pain and other symptoms [12] and that people in end stage dementia appear to receive less medication for pain although their symptoms are similar [13]. Complex care decisions are often needed such as whether to pursue active treatment e.g. antibiotics, whether to admit a resident to hospital and whether to commence tube feeding [12]. These take place in the context of patients unable to communicate verbally relying on family members as proxy decision makers [12]. Such challenges highlight the need for policy to address the knowledge and skill deficit in this area and models of care that address the complex and challenging care needs of people with advanced dementia [12]. There is increasing government recognition that more needs to be done in respect to all aspects of end of life care. A recent Australian Commonwealth Government report recognises the inadequacies [14].

"The current experience of end of life care in Australia is disparate and inconsistent and we cannot, in good faith, promise patients at the end of their life access to care that is customised to preferences and reliably delivers good symptom control. Our health system can do better".

Recommendation

Research funding should be made available to support the development of quality standards in end-of-life care. These standards are essential to help planners and policy makers design adequate service models, and to help clinicians understand what is expected from them. These models should be based on and incorporate patient and carer experiences in order to enhance the future care that structures these models. These models should encourage if not allow patients and carers to make choices about their care, and enable providers of care to monitor the quality of care delivery.

2. Patients' and Relatives' Awareness and Attitude: Consumers' Knowledge of Deterioration

Recent UTS Centre for Health Communication Research projects have highlighted the importance of knowledge held by families about what is happening to their patient relatives. This knowledge often proved critical to alerting clinicians to sudden deterioration, ensuring patients did not suffer unnecessarily, preventing the wrong medications or treatments being given, and making sure care was provided as needed. Yet this knowledge was often dismissed or regarded by clinicians as inconsequential to the unfolding care.

Recommendations

Clinicians should discuss and learn from patient and family experiences and knowledge to enhance the quality and safety of their end-of-life care. This approach should be integrated into awareness-raising programmes targeting discussion and debrief of death and dying experiences.

Because patients and their relatives may have intimate knowledge of care circumstances and have insight into potential improvements, **it is critical to strengthen patient engagement and participation in health care decision-making at the micro level of their own care, the meso level of general service provision, and the macro level of organisational planning and resourcing.**

3. Improved Advance Care Planning

While advanced care directives have gone some way in responding to unnecessary hospitalisation and unwanted treatments, their use is not widespread. Furthermore, without a fully integrated approach to implementation and community education, healthcare professionals are often left feeling uncertain about their role in enacting the plan, leaving no guarantee that patient wishes will be respected. Moreover, decisions made today may not be the same decisions that would be made under 'actual' circumstances [15]. Patients and families are expected to make complex decisions under stressful circumstances, and when emotions are running high. They are faced with the uncertainty of life and death, with dying significantly altering one's position and identity [16].

Recommendations

Evaluation of tools and models of care already developed to facilitate recognition of dying should be explored in the Australian context. For example The Gold Standards Framework developed by Dr Keri Thomas and her colleagues in the UK for use in the community and now adapted for implementation in Acute Care Settings and Aged Care Facilities and The Respecting Patient Choices Programme, an initiative originally piloted in Melbourne, and now being implemented inconsistently across several other states, including at John Hunter Hospital, Newcastle, NSW.

Such initiatives need to involve consultation with all stakeholders involved including GPs, Ambulance Services, Aged Care providers and Acute Facilities [17].

4. A Workforce to Care for Older Australians

All health and social care staff caring for older Australians will assist in the care of dying patients and their families at some time. Given that personal carers, including assistants in nursing make up 63.6 per cent of the workforce, basic skills in the palliative approach and caring for people with dementia are paramount. In particular, skills in end of life communication are a necessity.

Recommendation

All undergraduate, postgraduate and certificate courses should include preparation for end of life care. Care staff should receive orientation that includes basic communication training and cultural competency. Further, given the distress caused to staff in caring for dying residents whom they may have known for an extended period of time, **organisations need to ensure that support structures are in place for all levels of staff.** Models of care acknowledging the skill mix of the workforce should ensure support to untrained as well as trained workers in these areas. There are good examples of models of care that build capacity of aged care facilities in providing a palliative approach, such as the palliative link nurse programme in the Southern Highlands, NSW and the Palliative-Aged Care Nurse Consultant Model, South East Palliative Care, Victoria.

5. Future Spending on Care of Older Australians and End of Life Care
Community care levels in Australia are well below those seen in Europe [18]. The models used in Europe have shown benefits for patients as well as showing resource benefits.

Recommendations

Future funding models need to take account of the following:

- Increased requirements for Specialist Palliative Care services to meet the needs of people with non-cancer including the need for additional services to support palliative care provision in the community as well as residential and aged care facilities.
- Increased requirement for community care provision, developed in a way that builds on current service provision in jurisdictions rather than additional layers of service and funding. For example, provision for 'out of hours' services and affordable access to equipment and medicines.
- The need for workforce development outlined above.
- Improved research, evaluation and monitoring of end of life care.

We hope these recommendations will be integrated into your model.

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