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Voice of influence

Healthcare variation
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To Whom it May Concern

Re: Variation in healthcare

ACN welcomes the publication of the Australian Commission on Safety and Quality in Health Care's (ACSQHC) discussion paper, *Exploring Healthcare Variation in Australia: Analyses Resulting from an OECD Study.* The information presented in the document provides a valuable starting point for future research and discussion on variation in healthcare in Australia.

ACN has prepared responses to the consultation questions posed on page 4 of the discussion paper. In addition, ACN presents a case study of factors which influence variation in the care of people with Parkinson's Disease. ACN suggests that Parkinson's Disease and other chronic conditions could be considered in future work on healthcare variation undertaken by ACSQHC or other agencies.

Please do not hesitate to contact me for further information or discussion on this matter.

Yours sincerely

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7 July 2014

SUBMISSION DATE: 20/07/2014

Submission on Variation in Healthcare

Australian College of Nursing (ACN) is pleased to provide feedback on the Australian Commission on Safety and Quality in Healthcare's (ACSQHC) report, *Exploring Healthcare Variation in Australia: Analyses Resulting from an OECD Study*.

General comments

Including chronic conditions in future work on healthcare variation

ACN suggests that future work on healthcare variation should include content on chronic and progressive conditions. Chronic conditions affect a growing number of Australians and have an adverse impact on quality of life and life expectancy. They are one of the drivers of increasing health system costs, as well rising as out-of-pocket costs for consumers. People with chronic conditions face a range of barriers to accessing care, including the cost and local availability of services, potentially resulting in unwarranted healthcare variation. For this reason, the care of people with chronic conditions constitutes an important subject of research in healthcare variation.

International efforts to document variation in healthcare include chronic conditions. For example, the NHS Atlas of Variation in Healthcare Series publishes information on variation in the care of people with diabetes, respiratory disease and kidney disease. In ACN's view, it would be appropriate for Australian work on healthcare variation to include chronic conditions of relevance to Australian consumers, clinicians and policy makers.

Nursing services as a contributing factor to healthcare variation in chronic conditions

ACN notes that nurses working in hospitals, general practices and community-based nursing services make a critical contribution to the care of people with chronic conditions. For people with certain chronic conditions, the availability of appropriate nursing services may be a key determinant of variations in healthcare. For example, access to community mental health nurses can be one factor in determining whether or not a person who experiences an episodic exacerbation of a serious mental health condition requires in-patient treatment.

The availability of nursing services may determine treatment choices, particularly for people with certain chronic conditions, and as a result it would be appropriate to investigate access to these services in future work on healthcare variation.

Response to consultation questions

1. What is your position/role and your area of expertise?

Australian College of Nursing is a national professional organisation for nurses. As an organisation with members in all states and territories, health settings and nursing specialities, ACN is able to provide a broad and informed nursing perspective on healthcare variation.

This submission was informed by ACN members with backgrounds in public health, critical care, primary health care, mental health and movement disorders and Parkinson's nursing.

2. Is the information provided on the selected interventions in this paper useful in helping to identify variation? What further information or analysis is needed to identify potentially unwarranted variation?

Yes, the information on the selected interventions is useful in identifying variation, however more detailed information is needed to identify variation which is unwarranted. One approach would be to map both the rates of variation and factors which may contribute to variation. Information that could help to identify unwarranted variation and its causes includes:

- The distribution of health professionals (including specialist nurses and allied health care providers). Information about the distribution of clinicians is an indicator of access to healthcare, which can influence healthcare variation. If the rates of particular procedures are strongly correlated with the distribution of health professionals, this would suggest that this variation is unwarranted.

- More detailed socio-demographic data (such as information on the proportion of Indigenous people and people from culturally and linguistically diverse backgrounds in a population). If the rates of particular health care interventions are strongly linked to socio-demographic indicators, this would suggest that either access or health literacy may be driving healthcare variation.

- The availability of a range of primary health care services. In some instances, unwarranted variation in procedures performed in hospitals may be driven by inadequate access to community-based health care. For example, lack of access to appropriate podiatry services may influence rates of lower-limb amputations in people with diabetes. If healthcare variation in tertiary health services is correlated with the availability of primary health care, this would suggest that this variation is unwarranted.

3. Is the presentation of the information, the tables and graphs, useful?

Yes, overall the presentation of the information is useful. The tables and graphs included in the report give an informative snapshot of the variation in the rates of chosen procedures.

4. How should geographic groupings of patient residence be made in future – which units of analysis would be most helpful to explore healthcare variation in future?

The geographic groupings chosen for this work should be relevant to stakeholders, as this will help to ensure that the information is meaningful to policy-makers, consumer groups and clinicians. It would be beneficial to provide a number of different geographical groupings, as stakeholders operating at different levels are likely to have an interest in this work. For example, the Federal and state/territory health departments may wish to compare outcomes between states, while clinicians may be more

interested at comparing variation within a state/territory. Information should be provided at the level of Primary Health Networks (PHNs), Local Hospital Networks (LHNs) and states and territories.

Providing a number of different geographical groupings may also help to identify unwarranted variation. For example, jurisdictions provide differing levels of health care funding and services, and this is likely to result in unwarranted healthcare variation (see the case study on Parkinson's disease, below). If multiple geographical groupings at different levels are presented, it would provide information about whether the key determinants of variation are operating at the local, state or national level.

5. What can the Commonwealth, state and territory governments, private healthcare providers, primary and community health care providers and Local Hospital Networks do to reduce unwarranted variation?

ACN acknowledges that significant work is underway which is aimed directly or indirectly at reducing unwarranted healthcare variation in Australia. This work is being undertaken by governments and national bodies, with the involvement of clinician organisations and health services. Examples of specific initiatives that ACN is aware of include:

- Health Workforce Australia's national workforce planning projections for doctors, nurses and midwives (*Australia's Future Health Workforce* project, previously *Health Workforce 2025*)
- The National Health Performance Authority's reports on measures of health system performance, such as access to health care, immunisation rates and surgery waiting times
- Action plans developed by national organisations, such as the National Stroke Foundation's *National Action Plan for Stroke* and the Foundation for Alcohol Research & Education's *Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-16*
- Statewide clinical pathways, such as those developed by Queensland Health (http://www.health.qld.gov.au/caru/pathways)
- Clinical guidance developed by national organisations, such as ACSQHC, Cancer Australia and the Australia Resuscitation Council
- Partnerships between clinician organisations and governments to develop clinical guidance, for example, *A clinician's guide: Caring for people with gastrostomy tubes and devices*, currently under development by the NSW Agency for Clinical Innovation (ACI) and the Gastroenterological Nurses College of Australia (GENCA)
- The National Health and Medical Research Council's clinical practice guidelines portal (http://www.clinicalguidelines.gov.au)

However, Australia lacks a coordinated national strategy for documenting and addressing healthcare variation. As the list above illustrates, work to reduce healthcare variation is undertaken by a diverse range of organisations, operating without any shared framework or agreed national goals. In ACN's view, Australia needs a national strategy to identify priority areas of healthcare variation, develop targeted national goals and foster collaboration between governments, health services and national bodies.

The national strategy for addressing healthcare variation should focus on the following areas:

Health promotion through consumer empowerment

Work to reduce healthcare variation often focusses exclusively on healthcare professionals, without recognising that healthcare variation can be influenced by the social determinants of health and patients' ability to be involved in shared decision-making regarding their care. Greater investment in health education, health literacy and health promotion would help to empower consumers to be partners in their healthcare.

Developing a long-term health workforce strategy

Some of the unwarranted variation in healthcare may be due to the maldistribution of clinicians. The current distribution of the Australian health workforce does not necessarily correspond to population health needs. Developing a responsive, long-term health workforce strategy will help to address unwarranted healthcare variation (see Parkinson's case study, below). This work should be carried out at the national level, with input from local and state authorities, as well as clinicians and consumers.

Increasing access

Governments should consider how the distribution and accessibility of health services may be affecting unwarranted variation. For example, certain population groups rarely access the services of general practitioners. Disparities with regard to access are likely to be reflected in unwarranted healthcare variation and unequal health outcomes. Health services should be designed to meet the needs of the local population. Innovative models of healthcare (such as community-based nursing services or outreach services) may be needed to ensure all members of the community are able to access the right services at the right time.

Translational research

Commonwealth and state and territory governments should invest in and support translational research. Translational research promotes the widespread implementation of research findings in the clinical setting, thereby reducing variations in clinical practice. Translational research must be multidisciplinary and focussed on the patient's care journey from diagnosis to follow-up. In order to maximise its impact and reduce duplication, it should be integrated across jurisdictions.

Best practice models of care and quality improvement initiatives

Commonwealth and state governments should invest in the development, implementation and sharing of best-practice models of care. Evidence-based models of care support clinicians to deliver the right care at the right time.

Governments should implement system-wide quality improvement initiatives such as the Australian Primary Care Collaboratives Program (APCCP), which is a model for collaboratively developing, testing and implementing changes in participating general practices.

Health services should also support continuous quality improvement (CQI) initiatives, which can help to identify and address the causes of unwarranted variation in healthcare. For example, clinicians involved in CQI cycles may be able to identify areas where best-practice guidelines are not being followed and find solutions to ensure that patients are receiving the highest quality care.

Transparency

Governments and health providers should consider how they can increase transparency within the health system, for example with regard to clinical indicators and outcomes. Initiatives such as *MyHospitals* website (http://www.myhospitals.gov.au) could be expanded to include a wider range of indicators, including Nurse Sensitive Indicators. Increased transparency highlights healthcare variation and its causes and provides an incentive for health services to improve drivers of variation which may otherwise be invisible.

6. What role can clinicians and clinician organisations play to reduce unwarranted variation?

Clinicians should support patient decision-making by tailoring information about treatment options to the patient's level of health literacy and encouraging patients to use decision-aids. Good communication with patients helps to ensure that patient preferences and health needs are the determining factor in choosing an intervention.

Clinicians should ensure that they follow relevant clinical guidelines in their practice (where applicable) and participate in quality improvement initiatives, such as CQI cycles (described above) and interprofessional case reviews. Interprofessional case reviews draw on the different perspectives of members of the multidisciplinary team to identify how patient care can be improved.

Clinician organisations can help to reduce unwarranted variation by contributing to Australian clinical guidelines within their area of practice and by promoting these guidelines within their membership and more broadly. Clinician organisations should also draw attention to barriers to accessing healthcare in their area of practice and advocate for health system changes to increase accessibility.

7. What role can consumer organisations play to reduce unwarranted variation?

Consumer organisations can play a key role in reducing unwarranted variation by drawing attention to patterns of unwarranted variation and advocating on behalf of the people they represent. Consumer organisations can be involved in general consumer health education, health promotion activities and initiatives to raise awareness about particular conditions.

8. Are you aware of any local activity to identify and reduce unwarranted healthcare variation?

N/A (see question 5 for some of the initiatives ACN is aware of at the national and state/territory levels).

9. Production of a national Atlas of Variation is planned for 2014-15. Which groups and organisations should be involved?

ACN suggests that, in addition to organisations with expertise in acute care services, groups with a focus on primary health care should be involved in the production of the Atlas, as they will be able to provide insights into unwarranted variation in the treatment of people with chronic disease. A number of nursing associations have valuable information to contribute. For example, the ACN Movement Disorders and Parkinson's Community of Interest (COI) and the ACN Community and Primary Healthcare COI could be invited to contribute.

Organisations with a focus on rural and remote health should also be involved, as rurality appears to be one of the drivers of healthcare variation identified in the report. For example, CRANA*plus* and the National Rural Health Alliance (NRHA) may be able to provide insight into the causes of unwarranted healthcare variation in rural areas.

10. What areas or themes (conditions, treatments, interventions) should be explored for the Atlas? What specific aspects or activity should be explored?

ACN members identified a number of areas that should be explored for the Atlas because there is currently significant variation with regard to these conditions and treatments. ACN members believe further research and analysis is needed to determine whether or not this variation in unwarranted.

Conditions and treatments suggested by ACN members

- Chronic diseases (see general comments, above)
- Parkinson's Disease (see attached case study for further information)
- Renal calculi (kidney stones)
- Cataracts
- Obesity, particularly with regard to bariatric surgery
- Tonsillectomy and adenoidectomy
- Transurethral resection of the prostate
- Electroconvulsive therapy

In addition, ACN would like to reiterate the need to analyse other data which may illuminate the drivers of unwarranted variation, including data about the distribution of clinicians and primary health care services, as well as socio-demographic data (see question 2 for further information).

Case study: Parkinson's disease

This case study was developed with the assistance of the ACN Movement Disorders and Parkinson's Disease Community of Interest (COI) which is a group of registered nurses with expertise in the care of people with these disorders.

This case study is intended to illustrate why chronic and degenerative conditions such as Parkinson's disease should be included in the Atlas of Variation, and the importance of investigating access to specialist nursing care as one factor in unwarranted healthcare variation.

Background

Parkinson's Disease is a progressive, degenerative neurological disorder that affects motor function. Parkinson's may result in tremor, muscle rigidity, loss of voluntary movement and impairments in speech, balance and co-ordination. The prevalence of Parkinson's Disease is difficult to determine due to a lack of definitive diagnostic tests. In 2011, Deloitte Access Economics estimated that there were a total of 64,044 people with Parkinson's in Australia (Deloitte Access Economics 2011). The most accurate data is found in residents of aged care facilities, 8,100 (5%) of whom have a diagnosis of Parkinson's Disease as of 30 June 2011 (AIHW 2012).

The total financial cost of Parkinson's Disease per annum in 2011 was estimated by Deloitte at approximately $775.4 million. In addition, the burden of disease, or disability and premature death measured as Disability Adjusted Life Years (DALY) for Parkinson's Disease has been estimated at a cost of $7.6 billion for 2011 (Deloitte Access Economics 2011).

Parkinson's nurses

Access to a specialist Parkinson's nurse can be a key determinant of which treatment option is selected for a patient. Parkinson's nurses play an integral role in assessing which patients may be suitable for particular therapies, as well as delivering treatments. Parkinson's Nurses often spend significant periods of time assessing patients, including during home visits. As a result, they can contribute valuable information about a patient's suitability for a particular treatment. Parkinson's nurses also provide help with medication management, technical assistance for treatment devices and assistance in managing treatment side effects.

Parkinson's nurses play a pivotal role in care-coordination. Regular review and assessment by a Parkinson's nurse complements the role of the neurologist in identifying patients' complex care needs. Parkinson's nurses are able to refer patients to the appropriate services such as speech therapy and palliative care for early intervention as required. Patients without access to a Parkinson's nurse may have greater difficulty in accessing necessary support and services, particularly in rural areas.

Access to a Parkinson's nurse is largely determined by state or territory of residence. Currently, there are an estimated 35 Parkinson's nurses working in Australia, most of whom most of whom are employed in the public health systems. However, funding for Parkinson's nursing services is highly variable. For example, Western Australia has a successful model of community-based care delivered by Parkinson's nurses. In contrast, there are no Parkinson's nurses employed in the Northern Territory.

Treatments for Parkinson's disease

In the early stages of Parkinson's disease, many symptoms can be successfully controlled with the medication Levodopa. However, in the advanced stages of Parkinson's disease, symptoms often become severe, unpredictable and resistant to treatment with Levodopa. At this stage of the disease, advanced treatments are required, which may include apomorphine injections or infusions, intestinal duodopa and deep brain stimulation. Whether or not patients are able to access these advanced treatments may depend on where the patient lives, government funding for treatments and access to appropriate nursing services.

All three advanced therapies described below are complex treatments. They are delivered at specialist centres with expertise in Parkinson's and which have systems in place to support patients on an ongoing basis. Patients return home after the initiation of treatment, where they are cared for by their usual treating team with distance support from the specialist centre. This is known as the hub and spoke model of specialist care, which requires an appropriate workforce in order to function effectively.

Apomorphine

Apomorphine is given by intermittent subcutaneous injections or by continuous infusion delivered by a pump. Patients using apomorphine need to purchase consumables including needles, tubing and dressings.

While apomorphine is listed on the Pharmaceutical Benefits Schedule, most state and territory health services do not cover the cost of supplying consumables to outpatients. The full suite of consumables required for a month of apomorphine therapy can cost patients over $200 out of pocket.[1] The lack of funding for apomorphine consumables may be one of the drivers of variation in the use of this therapy, as people on lower incomes may be unable to afford the consumables.

Apomorphine therapy is usually initiated and supported by specialist Parkinson's nurses. Parkinson's nurses provide patients with education on the medication, aseptic technique, injection technique, troubleshooting issues as they arise and information on managing side effects. In some instances, access to appropriate nursing care may influence whether or not apomorphine treatment can be offered to a patient.

Intestinal duodopa

Duodopa is delivered in the form of a concentrated gel via a patient-controlled pump attached to a percutaneous gastrostomy tube. Parkinson's nurses provide patients with ongoing technical support for the operation of the pump, care of the gastrostomy site and medication management. Duodopa may not be offered to a patient if the support of specialist nurses is not available.

Deep brain stimulation surgery and follow-up care

Deep-brain stimulation (DBS) involves implanting a pulse-generating device into the patient's brain. DBS is a highly specialised procedure which is offered in a small number of surgical centres around Australia. As mentioned above, Parkinson's nurses play an important role in helping to identify candidates for DBS surgery.

Post-operatively, the settings of the implanted pulse generator are adjusted by a neurologist and/or a Parkinson's nurse. In areas where there is no local neurologist, Parkinson's nurses provide most of the follow-up care for DBS patients and ensure that the pulse generator is adjusted as necessary. DBS surgery may not be offered to patients if no nursing support is available.

[1] The cost of a month's supply of syringes, saline solution ampoules and infusions lines can be as much as $207.97.

Access to DBS surgery may also be influenced by the state the patient resides in and the patient's private financial resources. Medicare funds some of the item costs associated with DBS, but patients are usually required to pay a gap fee if the procedure is carried out in a private hospital. Some states, such as Western Australia and New South Wales, fund a limited number of DBS procedures in the public hospital system. However in other states and territories DBS is not accessible to public patients. The out-of-pocket cost of surgery may be one factor driving unwarranted variation in the provision of DBS.

Conclusion

Parkinson's disease is a chronic, degenerative disease which affects a large number of Australians. While a number of effective therapies are available, access to these therapies is determined by a range of factors unrelated to a patient's individual needs and preferences, resulting in unwarranted variation. Including Parkinson's disease in the Atlas of Variation would be an important step towards documenting this unwarranted variation and precisely identifying its causes. Given the growing burden of chronic disease, ACN suggests that chronic diseases more generally should be a focus of future work on healthcare variation.

References

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