Integrated and consumer directed care:

A necessary paradigm shift for rural chronic ill health

Abstract

Chronic Ill health has emerged as the most important health issue globally. Rural communities are disproportionally affected by chronic ill health. Many health systems are centred on the management of acute conditions, and often are ill-equipped to deal with chronic ill health. Cardiovascular disease (CVD) is one of the most prominent chronic ill health conditions and the principle cause of mortality worldwide. CVD is used as an example to demonstrate the disparity between rural and urban experience of chronic ill health, access to medical care and clinical outcomes. Advances have been made to address chronic ill health through improving self management strategies, health literacy and access to medical services. However, given the higher incidence of chronic health conditions and poorer clinical outcomes in rural communities, it is imperative for the integration of health care to emphasise greater collaboration between services. It is also vital to better support rural GPs to work with their patients, using consumer-directed approaches to empower patients to direct and coordinate their own care.

Keywords: Rural health, chronic disease, consumer-directed care, integrated care, quality of health care

What is known about the topic?

- Health systems are geared toward acute health conditions and are ill-equipped for chronic ill health issues and health service delivery is deeply entrenched by powerlessness of the consumer.

What does this paper add?

- This analysis focuses on chronic ill health in rural Australia that has wider implications regarding its impact on integrated care for rural people internationally and contributes to the current debate.

Introduction

Chronic ill health has become an increasingly important issue for health services in both developed and developing countries, as it accounts for 63% of all deaths globally (The World Bank, 2013, p.). Chronic ill health consumes a large proportion of total health expenditure across many countries and will have an estimated global economic impact of more than US$47 trillion over the next two decades (representing 62.7% of 2013 global GDP) (Abegunde et al., 2007, p; Bloom et al., 2012, p; The World Bank, 2013, p.).

Chronic ill health conditions predominantly affect older people, but are increasingly observed among younger populations (Gore et al., 2011, p.). The increasing prevalence of chronic ill health conditions, such as diabetes, chronic obstructive pulmonary disease (COPD), chronic kidney disease (CKD), cardiovascular disease (CVD), and cancer has occurred as a result of a number of social determinants of health. Poor health behaviours, including dietary habits, insufficient physical activity and other lifestyle factors have also contributed to the burden of chronic ill health (Nolte and McKee, 2008, p.).

Health systems are geared toward the management and treatment of acute health conditions, and are often ill-equipped to manage chronic ill health issues (Nolte and McKee, 2008, p.). These issues include multiple hospital admissions, lengthy disease periods and numerous co-morbidities (Nolte and McKee, 2008, p.). People with chronic ill health conditions often use multiple health providers simultaneously which requires greater integration and coordination of care that focuses on consumer-directed approaches (Nolte and McKee, 2008, p.).

The challenge is that in the face of increasingly austere health budgets, there is a need for change within health systems that addresses the chronic ill health crisis, while working with and towards increasing the autonomy and independence of health consumers (Kodner, 2003, p.).

Chronic ill health in rural contexts

Rural communities in geographically vast countries, such as Australia, Canada and the United States, are unique. Rural people shoulder a greater proportion of the chronic ill health burden, particularly older, Indigenous and socioeconomically disadvantaged people (Bourke

et al., 2012, p.). Rural populations encounter difficulty accessing the medical system due to cost, time, distance and accessibility of health professionals (Bourke et al., 2012, p.).

Although improvements in screening rates, early detection and an overall reduction in mortality for certain conditions have occurred, these improvements have often had less impact in rural communities (Clark et al., 2007, p.). Patients may not receive adequate care, ongoing monitoring or access to specialist management programs. In these circumstances, rural and remote communities experience health care where demand outstrips supply (Astley et al., 2011, p.).

Significant inroads can be made by developing self management strategies, health literacy and attempting to improve access to medical services in rural areas (Lê et al., 2013, p.). However, 'integrated care' requires a 'top-down' approach that is emphasised by greater organisational, clinical and funding collaboration between services (Fortin et al., 2013, p.). In addition, integration also encompasses 'consumer-directed care' that requires a 'bottom-up' approach and is emphasised by empowering patients to direct and coordinate their own care (Kodner, 2003, p.). These two approaches are required to develop a truly integrated services in rural areas and remain critical to improve health clinical outcomes (National Heart Foundation of Australia, 2013, p.).

Approaches such as consumer-directed care are required to be implemented to enhance the lives of individuals, particularly those with chronic illness or disabilities. Consumer-directed care allows consumers greater self determination and control over their health and lives. The process ensures greater consumer choice, while enabling consumers to make greater decisions concerning their needs, the care they require and the quality of care they receive (Kodner, 2003, p.).

These consumer-directed approaches have been used to inform the development of health services across Australia and internationally, particularly when focused on specific aspects of care (Kodner, 2003, p.). A number of these approaches, outlined in Table 1, highlight the micro, meso and macro level approaches of integrated and consumer directed care. However, to be truly consumer-directed, the process identifies the factors that may impact consumers and allows opportunities to empower and improve consumer outcomes, service efficiency, and sustainability. The approach promotes mutual collaboration and support between the health care provider and patient (Kodner, 2003, p.).

Table 1: ***Approaches to integrated and consumer directed care***

Micro-level approaches	Meso-level approaches	Macro-level approaches
1. Consumer-directed focus	1. Tools and processes to assist GPs to	1. Integrated data linkage systems
2. Patient-centred focus	- Optimise short consultations	- Knowledge exchange and resources sharing
3. Care coordination involving the consumer	- Engage patients with self-directed health decision making and patient-centred care	- Data repositories to link patient information and consumer-directed care
4. Specific care tailored for individuals	2. Management guidelines that may include	- Real-time decision-making, clinical effectiveness and evidence based practice
5. Develop self management strategies	- Absolute-risk-based screening	- Internet based primary care programs, such as cardiac rehabilitation
6. Improve health literacy	- Multi-factorial recommendations	- Use of telehealth to link primary and specialist care
7. Change individual expectations of health care	3. Improve primary and secondary care provider patient information exchange	2. Change community expectations of inequitable health care

The example of cardiovascular disease in Australia

Cardiovascular disease is the leading cause of mortality worldwide, including Australia (National Heart Foundation of Australia, 2013, p.). It accounts for healthcare expenditure of more than AUD$1 billion per annum and substantial proportion of practitioner workload (National Heart Foundation of Australia, 2013, p.). The medical workforce shortage in regional and rural Australia means many people have limited or no access to cardiologists when and where they need them and they are more likely to be managed by a General Practitioner (GP) (Teng et al., 2014, p.).

General Practitioners are well situated to provide holistic, personalised and integrated care approaches, as they work across clinical boundaries and at times act to bridge gaps that may occur between clinical and social issues (Kodner and Spreeuwenberg, 2002, p.). As integrated care is collectively pooled with consumer-directed care approaches within rural settings, patients are further empowered to work flexibly with GPs. Patients are enabled to participate in their own care which leads to greater quality and satisfaction without impacting effectiveness and funding of health systems (Kodner, 2003, p.).

Gaps in primary and secondary prevention of cardiovascular disease

The decline in mortality rates from CVD in countries such as the United States are equally attributable to the reduction in CVD risk factors and improved medical and surgical therapies (Ford et al., 2007, p.). This emphasises the importance of effective and coordinated primary and secondary prevention and consumer-directed care. Addressing key risk factors and involving people, who are predisposed to CVD, with their own health care is essential to prevent the development of the disease (Kodner, 2003, p.).

However, many GPs do not routinely calculate absolute CVD risk (Montgomery et al., 2000, p.). In addition, many patients are not receiving advice from their GPs or are not actively engaged with medical advice that leads to appropriate lifestyle modification (Crouch et al., 2011, p.). These factors may explain the large number of patients who do not understand the significance of their CVD risk (Montgomery et al., 2000, p.). Nevertheless, not receiving adequate advice or being less involved with their own care may be due to a number of intrinsic or extrinsic factors such as individual time constraints, or a product of a fee-for-service system that leads to multiple short consultations (Britt and Miller, 2013, p.).

As a solution, consumer-directed care has the potential to reduce GP workload, decrease health expenditure and empower patients concerning their health as they can be part of the care and decision making process (Kodner and Spreeuwenberg, 2002, p; Kodner, 2003, p.). Consumers become better informed about medications and be more involved in health decision making that leads to greater compliance (Heeley et al., 2010, p.). If primary and secondary prevention is to be effective it is important that patients are involved with their care and be actively engaged with the process (Bourke et al., 2012, p.).

Barriers to effective primary care in regional and rural contexts

Inequities in access to health care for rural residents compared to their urban counterparts contribute to a divide in CVD management (Russell et al., 2013, p.). These inequities include fewer primary and specialty care practitioners, lower rates of government subsidised health care, lower average incomes, and greater travel for specialist medical care (Russell et al., 2013, p.). In addition, patients in rural and remote areas visit the GP on fewer occasions per year than urban patients and may only be offered health promotion and risk management opportunistically (Nelson and Doust, 2013, p.). Whilst most of these factors are applicable to all locations in Australia, they are likely exacerbated in rural areas where factors such as

education, income, cultural background and language have a bearing on the health of the community (Bourke et al., 2012, p.).

Some of these issues that have been indentified may be resolved with the synthesis of a single CVD risk management guideline that combines absolute-risk-based screening with multi-factorial recommendations on management. Further, a greater coordination and integration of care would be required to focus on consumer-directed approaches that empowers and improves rural patient autonomy, while respecting individual choice (Webster et al., 2009, p.). Tools and processes may need to be developed to assist GPs to optimise short consultations and engage with patients with self directed health decision making (Harris et al., 2013, p.).

The need for properly integrated CVD management

The effective management of CVD for all patients requires the translation of evidence to clinical practice (Harris et al., 2013, p.). In the past, efforts to record CVD management details in medical registries have been limited by insufficient infrastructure and resources (Harris et al., 2013, p; Liaw et al., 2012, p.). Currently, there is considerable variability in patient information exchanged between primary and secondary care providers (Liaw et al., 2012, p.). Comprehensive data would enable health information exchange, lead to improvement of services as well as reduced healthcare costs.

Better coordination and planning of health care that involves the consumer, is central to reducing CVD morbidity and mortality. As such, there is an urgent need for effective and reliable data repositories, to be used by primary and secondary care centres that capture information regarding treatment and outcomes (Gregory et al., 2006, p.). This data would provide the capacity to evaluate and change in-patient and system level care among patients with, or at risk of CVD, while providing a suite of sustainable interventions that could be shared across multiple health services (Astley et al., 2011, p.).

There are many examples of innovative primary health care models in rural and remote areas. Multidisciplinary teams, along with local communities plan and develop local models that deliver the CVD care rural populations require (Humphreys, 2008, p.). Innovations such as internet based cardiac rehabilitation programs in rural primary care, and increasing the provision of telehealth to bridge the link between primary and specialist care for rural

patients are vital (Moffatt and Eley, 2010, p.). However, such innovations are often local solutions that have been devised to meet a specific need.

Currently, data linkage practices in Australia lack coherency are clumsy and are unnecessarily complex (Astley et al., 2011, p; Buykx et al., 2012, p.). Health care facilities and primary practices have their own data systems, however they often do not talk with or 'cross pollinate' patient information and successful consumer-directed care approaches. This inability impacts individual care and creates systemic challenges, such as complicating real-time decision-making, clinical effectiveness and overall evidence based practices (Astley et al., 2011, p; Buykx et al., 2012, p.).

Integrated systems provide the opportunity for greater knowledge exchange and sharing of resources across clinical care spheres, especially in rural areas. Lastly, patient-centred care can be specifically tailored for individual client needs, where the patient's journey can be tracked and understood more clearly (Astley et al., 2011, p; Buykx et al., 2012, p.).

A change in expectation

Beyond systems that more comprehensively share data and improve care, there is a need to raise people's expectations of equitable health care in non-urban areas. In countries, such as the United Kingdom (UK), community criticism of inequitable and discriminatory access to care, based on where a patient resides, or 'Postcode lottery' resulted in significant amendments to the health care system (Cummins et al., 2007, p.).

In Australia, a level of acceptance or even apathy persists among rural people regarding inequitable health care with a disinclination to drive health policy (Philippon and Braithwaite, 2008, p.). It is not clear why this situation persists in Australia, given that other western countries have fought similar inequities with strong media coverage, public objection and have driven changes in health policy (Philippon and Braithwaite, 2008, p; Cummins et al., 2007, p.).

The differences in attitudes toward chronic disease, cancer and health outcomes between metropolitan and rural populations may be due to differing beliefs, values and health expectations that occur in rural areas. For example, some rural communities may exhibit fatalistic beliefs, stoicism, or general acceptance regarding inequitable health care (Howat et al., 2006, p; Befort et al., 2013, p.).

Discourses regarding health service delivery within rural and regional Australia is deeply entrenched due to a rural individual's sense of powerlessness and despondency (Mahoney et al., 2001, p.). It has also been proposed that attitudes concerning health and health care knowledge arises from learned definitions of illness (Mahoney et al., 2001, p.). Overall, the understanding and perception of health and wellbeing is developed through the disempowerment of rural communities which is compounded by community size, cohesion and isolation.

Herbert-Cheshire (2000, p.) suggests that there needs to be a shift in individual and community expectations in rural areas, from the 'victim consciousness' to a situation of empowerment. Individuals and groups need to become active participants in their own health and future health of their community through approaches such as consumer-directed care (Kodner, 2003, p.).

Conclusion

Rural people experience an increased risk of developing chronic ill health conditions such as cardiovascular disease; are typically diagnosed at an advanced stage; and experience increased rates of mortality. The Australian health system, as with other health systems, needs to be reoriented to meet the needs of patients with chronic ill health, particularly in rural areas. Rural Australia has continually devised innovative ways to meet patient needs amid financial and workforce constraints and the challenge of chronic ill health will be no different.

It is time for new thinking concerning integrated care, consumer-directed care and health system approaches. It is also time to address the contribution of lifestyle factors and health behaviours to the burden of chronic ill health, while better supporting GPs to work with their patients in tackling these issues. There is a need to better understand rural Australia's acceptance of health inequities and the attitudes that underpin this acceptance. To achieve this there is a need for a paradigm shift concerning access to care, greater patient and primary healthcare team access to education and advice when required; and IT links for the transfer of health care information between healthcare teams.

General practitioners are well placed "to take a comprehensive, person-centred approach, including exercising responsibility for the co-ordination of care" (Kodner and Spreeuwenberg, 2002, p. e13), particularly in rural areas as they reach about 90% of

Australians each year.[8] In order to tackle rural disparities, particularly chronic ill health, it is timely for regional and rural primary care services to embrace consumer-directed care and be linked to specialist metropolitan-based services through the provision of fully integrated care. Tackling these disparities with anything less may lead to local improvements but not the paradigm shift that is required to break the deadly synergy between chronic disease outcomes, such as CVD, and distance from metropolitan centres in Australia.

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