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Short Commentary

The Challenge of Integrated Care

Stephen R Leeder[1]* and Christopher Kazuma Thien-Tam Le[2]

[1]Emeritus Professor of Public Health and Community Medicine at the University of Sydney, Australia

[2]Early Career Researcher Based in Sydney, With Experience in Advocacy and Policy Work in Public Health, Australia

Corresponding author: Stephen R Leeder, Emeritus Professor of Public Health and Community Medicine at the University of Sydney, Australia; **E-mail:** stephen.leeder@sydney.edu.au

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Introduction

Serious and continuing illnesses have risen to prominence everywhere with generally increased life expectancy and somewhat fewer threats to health and life due to acute illness [1]. Health care systems that invest heavily in acute hospitals are recognising the need to repurpose services to include care beyond their walls to where people with prevalent chronic illnesses live. Multiple services – both medical and social and often low-tech – are required by patients with multiple morbidities, not the stock-in-trade of many major hospitals.

Now, the intention is to provide care for the patient as an individual rather than as a recipient of separate programs of care for his or her several separate medical problems (arthritis, heart disease and mild dementia). Anecdotes tell of four cars parked outside the home of a patient with multimorbidity, each bearing a therapist for one aspect of the patient's problems. Chronic diseases such as those mentioned are the leading cause of death in Australia, with over 51% of hospitalisations and 89% of deaths associated with chronic disease [1]. They also cause a large out-of-pocket burden for many, with as many as 78% of Chronic Obstructive Pulmonary Disease (COPD) patients experiencing economic hardship while managing their illness [2]. Many chronic diseases are preventable [3], but despite this, preventative health makes up only 1.3% of all health spending [4], begging the question 'Is it time we evaluated our current system?'.

'Integrated care' refers to the concern to improve the overall patient experience, from prevention to post-discharge care, and attain both greater value and efficiency from our health delivery model. It aims to address the fragmentation which often occurs in patient services; through integrated care the hope is that now the patient will benefit from a more holistic, joined-up service so that useless duplication and inappropriate admissions to hospital will be reduced.

In Australia, which enjoys high levels of health and generous financial investment in health care, much experimentation has occurred with different configurations of integrated care (as this joined-up pattern of hospital and community care is termed). In western Sydney, two programs (among many) conducted in recent years give insights into what can be done with modest investment and decisive management to improve the quality of life of patients with multiple chronic problems. The two small examples with which we are familiar, do not provide a clear set of directions about what to do in providing integrated care. Rather, because of our marginal involvement in them we been able to observe their operation and note what works well.

The Respiratory Ambulatory Care Service (RACS)

To assist patients with severe chronic obstructive lung disease (and usually other problems as well), this program was established by Professor John Wheatley, a respiratory physician at Westmead Hospital, ably assisted by Mary Roberts, a nurse practitioner, at Blacktown Hospital in 2001 with NSW Health Chronic and Complex Care funding. Over the years it was modified to meet the needs of the population [5]. The program had 8 pulmonary rehabilitation classes a day across Western Sydney Local Health District, with 12 patients enrolled in each class, with a text message support service which had over 100 patients enrolled in the Breathlessness Clinic. These patients were assessed at Blacktown Hospital by a physician, a physiotherapist, and a nurse.

Initially starting as a pure pulmonary rehabilitation program, it developed into a comprehensive COPD management program with a 24-hour helpline with COPD action plans [6]. A ten-week program of exercises and support was arranged for each patient. They were then cared for at home by the ambulatory team with regular visits by the nurses. A laptop-based medical record was maintained for each patient. The laptop passed to the duty nurse each night. Each patient was encouraged to contact the team by phone if they had a problem, and many did, especially at night when an attack of breathlessness might lead to panic which, without the support of the RACS, usually led to an ambulance call to take them to the hospital emergency department.

A conversation at 2 am with a nurse who knew the patient and had their electronic record in front of them on their laptop, could help decide if hospital admission (the default option in the absence of someone to speak to, with massive social dislocation to the patient and expense to the health service) is required or whether the patient can be 'talked down' and reassured to go back to bed, their problem to be fully explored, at home, in daylight. Past patients also had access to this 24-hour helpline which was utilised by patients who had not been in years, and a monthly subscription newsletter for education and information.

The program has been fully described in publications [6] SRL assisted for two years as a respiratory physician, servicing a clinic once a week and occasionally accompanying the nurses on home visits.

The program was established by Wheatley because he saw how patients once beyond the hospital could easily flounder for lack of specialised support. General practitioners often did not have the time or the access to resources available to the RACS team. By maintaining strong links between the specialists and the nurse led RACS team, integration was achieved. The results of the program were impressive with hospital admissions halved among program participants in the year after enrolment compared with the year before. Furthermore, during ongoing the COVID-19 pandemic, RACS was altered to provide telehealth and tele-education, as well as text messaging support. This not only is a great example of how such a system can evolve to suit the needs of the population, but a potential glimpse into the future.

Perhaps the most important caution is that health service managers should not be seduced into supporting integrated care programs because they believe they save money (they may) but rather should support them because they lead to a better quality of life for enrolled patients, albeit often at increased cost. It is misleading in the long-term to promise without evidence that 'integrated care reduces hospital costs by keeping people out of hospital.'

Worldwide, the demand for hospital beds is such that if a bed is emptied because a chronically ill patient is cared for in the community instead, it is quickly filled by someone else (say, with a femoral neck fracture) and the costs to the health system remain unchanged. Clinicians know this and their interest in integrated care is because it is good medicine, not because it is cheap. In recruiting clinical staff to integrated care programs it is important to make this point strongly.

The Western Sydney Integrated Care Demonstrator Project

In 2016, the New South Wales (NSW) Ministry of Health provided affirmative funding to several health districts to support demonstration projects in integrated care. An allocation to the Western Sydney Local Health District enabled the development, again with a nurse manager and this time an extensive team of health professionals of different disciplinary skills and interests from both the hospital and the community, in relation to the care of patients with diabetes, heart disease and cardiovascular problems.

Although these three disease themes were developed relatively independently, they were linked through patient recruitment and documentation. Hospital specialists were critical to the development and implementation of the project as were local general practitioners. Nurses played a pivotal role in making the program happen, assisting greatly in the recruitment of patients both in Westmead Hospital and the western Sydney community through general practice.

This was a more complex program than RACS and required more managerial effort because of the number and diversity of practitioners involved and because the motivation for the program was 'top down', i.e., it came from NSW Health primarily rather than from practitioner concerns for better care of their patients. Practitioners needed education and support to be persuaded to participate.

The program used several strategies, including care facilitators, extensive use of IT, action plans for specialist care, shared care plans, the establishment of a rapid access and stabilisation service for patients that avoided them having to use the Emergency Department if they deteriorated, support payments to general practices to enrol and document the progress of enrolees, and promotion of the concept of a patient centred medical home.

Qualitative evaluation of the program was conducted, and the results are detailed in two papers by the principal evaluation research person [7,8]. SRL chaired the evaluation research advisory committee for the program.

Conclusion

There are several takeaway messages from these two programs. First, there is a big challenge in bringing the multiple players, both in the community and in the hospital, into a harmonious and productive team. This requires sensitivity and professional management. Effective integrated care relies on negotiation among several professional groups and separate government agencies, e.g., health and social services. Second, the recruitment of patients to these programs necessitates patient explanation and a responsiveness to questions that patients will have about their continuing care. People who are sick are frequently anxious not only about their health but also about the adequacy and dependability of their care. Familiarity with one or more carers, often a nurse, is important to achieve continued participation by patients and their carers.

Third, integrated care programs must be well organised and managed and this requires resources both in terms of workforce and money. The lines of responsibility (and accountability) are often long and intertwined and it is unusual for this arrangement to proceed smoothly in every respect. Negotiation is needed at many points in the program and once again time and patience are needed. The development of tailored IT arrangements to enable integrated care is critical and time-consuming.

Fourth – and there is a serious risk here – the program may be hijacked by managers who are ignorant of the detail of effective integrated care and see it as a way to save money. This is implausible [9] and can lead to program failure. Advocacy for the program is essential at all stages. In this regard it is very helpful to have leadership in the management of the program by senior and respected clinicians, both in the hospital and also in the community.

Fifth, the evaluation of integrated care programs is difficult because of the complexity of the relations among different groups of players. Comparison of patients managed conventionally and via integrated care is hard to engineer to the rigorous standards of a randomised controlled trial. The outcomes desired from integrated care often have to do with marginal improvement in quality of life. Even using an end-point such as reductions in hospital admissions can miss the point: some patients may need more rather than fewer admissions if the integrated care program brings to light problems that were previously not managed or not managed well.

In conclusion, the use of integrated care for the optimal management of patients with complex, serious, and continuing illness offers advantages especially for those living outside institutions and not

in hospitals or care homes. An effective integrated care program should include aspects of an increased focus on preventative and population health, changes to the patients experience while admitted in hospitals, and higher levels of community support and care for patients outside of hospital walls [10]. Although in its early stages of development, it is attracting great interest among patients, their carers and families, and clinicians seeking to offer them the best quality of care.

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