

n=1: Some challenges and opportunities for integrating patient care

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I AM A JUNIOR DOCTOR working in a Brisbane hospital. I recently completed a PhD investigating the use of eHealth strategies to improve community access to relevant health information, with a particular focus on low socioeconomic communities and their needs.¹ Like many products of the postgraduate medical course, I came to medicine after studying other disciplines — economics and government as part of a Bachelor of Arts, and medical sciences as part of a Bachelor of Science. I've long had an interest in policy, and after several years of community-based field work in a community with an average household income of \$25 000, and two years of hospital-based clinical experience, I have come to realise that the health system fails to integrate services to provide a systematic approach to dealing with patients' needs.

In this *n=1* I outline some of the deficiencies I encounter in everyday clinical practice, from admission to discharge, and beyond, to community-based care. Let me make it clear at the outset that I believe these deficits do not arise from a lack of compassion or care on the behalf of dedicated clinicians and hospital support staff, but rather from a system failure. Indeed, in my own experience, most health care workers give too much, to the detriment of their own health and quality of life. Some of my comments are supported by "systematic research" (field-based observation and survey data), while others come from my own daily encounters.

Impact of information limitations on patient care

I'll start with my outline of a typical hospital admission through the Emergency Department. The patient presents the emergency doctor (having seen a nurse first) with a list of symptoms and signs. The patient and his or her family members are in distress; there are questions (but not many answers) and concerns (some immediate and some longstanding); a past history of medical complaints (often poorly understood and incompletely remembered); and usually no hospital chart available (it is in medical records down in the basement).

The emergency doctor considers: What am I dealing with? Is it deadly? Is the patient stable or unstable? What can I do NOW — symptom relief and immediate treatment? What do I need to find out — what tests can I run? What is the past history? Is the general practitioner available? (No, it is I am). What are the usual medications? (Does the patient use one pharmacy? Do they have one GP with a list of medications? Do they have several specialists who prescribe different medications? Have these specialists altered medications prescribed by other specialists?)

The patient gets admitted — usually much better than before — with a preliminary plan enacted after discussion with the admitting specialist (eg, cardiologist, respiratory physician, or general physician). Usually the patient is seen within 24 hours by the admitting specialist or junior doctor working in the team. By this point most of the preliminary results, such as radiology and blood tests, are available and many of the physical manifestations and symptoms have resolved (at least in part). We have an evolving condition with patient–doctor, patient–nurse, family–doctor and family–nurse encounters

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occurring throughout — creating many opportunities for miscommunication and forgotten requests. *We have an ad hoc approach to obtaining information as well as disseminating it.*

Usually the patient has many questions: What is wrong? Is it serious? What can you do? What can I do? How long will I be here? The family also has many of the same and some new questions. Who answers the questions? Sometimes it is the doctor; sometimes it is the nurse, and sometimes they remain unanswered. It is hard for these answers to always be “correct”, because inevitably patient care is a dynamic, evolving process. To complicate the situation, new conditions often arise in hospital (a heart attack, pneumonia, a fall . . .).

Throughout the episode a lot of important information is collected; tests which establish the patient's baseline function, the pathology, the active health issues and those dormant, waiting to rise again. Where does the information go? Into the chart? Into the doctors' or nurses' memories, or into the ether? Is this good enough?

Then comes the time for discharge; the patient is well and they leave hospital with some pills and (hopefully) a healed body. A letter will be sent some time later; usually to the GP (to the GP who saw them and sent them to hospital or their regular GP?), very infrequently the letter goes to the patient. Often the patient presents with the same problem to a different hospital — the cycle repeats, none the wiser for all the work done before . . .

Unfortunately, I see this situation occurring in many admissions. Sometimes as part of the admitting team I am lucky, and someone else has summarised the information either in a letter or in a previous admission, but usually so much has to be repeated (tests, questions, recovering information from other hospitals and GPs) with waste and duplication. Imagine the savings if we could do this better!

Involving patients in their care

The time of paternalistic clinical care is past; patients should be partners in their care. The

patient needs to become an active participant in their health and the health system needs to become better at facilitating this. At the very least patients need to know what is wrong with them, how they can help themselves (in hospital and out of hospital), when to ask for help and who to ask (when should they see their GP and when should they come to emergency?).

One means of providing such information and bringing the patient into a partnership with clinical staff is a clinical pathway. In 2002 I did some work for the Royal Australian and New Zealand College of Psychiatrists on clinical pathways and realised that, not only can these coordinate clinical care by providing a road map of a “typical” hospital stay, but they can also provide a means of educating and empowering patients.² However, even though the ultimate goal is the same, there is a need for two separate pathways: a patient clinical pathway and a hospital clinical pathway — both of which result in the discharge of a well patient. Clinical staff need task- and process-specific information (but this information should not be exhaustive and too specific — the problem with most clinical pathways). Patients need to know where they stand during a typical hospital stay, what the treatment plan is and how this will be continued in the community. Every time I see a new patient I determine the diagnosis and necessary treatment and explain both to the patient (with some education about the patho-physiology if I can) and end the consultation with some information about how long I expect them to be in hospital. I believe there is nothing more disempowering than uncertainty, and a disempowered patient can take longer to heal. A patient-oriented clinical pathway provides concrete information and an ideal launch pad for patient health education. Why aren't we educating patients in hospital? This is the time when they are most interested in their condition and most inspired to act. Indeed, many patients re-present to hospital because of our failure to properly educate.

As part of my PhD I investigated a health information prescription service.^{1,3,4} A patient information prescription allows doctors to pre-

scribe information sub-groups which would aid the patient in managing their health concerns. For example, a 60-year-old man with diabetes and ischaemic heart disease needs education regarding the symptoms of ischaemic heart disease (eg, the difference between angina and a heart attack); their diabetes and the management of their blood glucose levels; dietary optimisation for risk factor reduction; an optimal exercise routine for weight loss and cardiovascular fitness; information regarding yearly screening such as renal function, ophthalmology reviews, podiatry reviews and blood pressure monitoring; as well as ad hoc education regarding the treatment and prevention of conditions as they arise (eg, cellulitis and other opportunistic infections).

Sometimes patients are provided with such information (especially if they see a diabetic care nurse or diabetes counsellor) but for many other conditions there is no such education pathway and patients are left to their own devices (the Internet, support groups, and sporadic education from their GP). In the same way we have employed the “Asthma management plan”, we need to provide similar guidance for other common and important conditions. Such work is occurring in some hospitals and some disciplines — for example cardiac rehabilitation programs — but these do not apply to most conditions.

I am often asked why doctors are not providing this information themselves, and largely I believe it is the result of the constraints of clinical practice (too few doctors and too many patients). Doctors are principally trained in the diagnosis and management of conditions; the depth of knowledge required of a clinician is greater than that required to provide adequate and appropriate health information. This is not a narcissistic view but a practical one. Doctors are trained to be detectives, deciding which the most pressing health complaint is and what we can do about it. Non-medical, auxiliary health personnel could provide effective (and perhaps better) health education.

Adequate health education requires several presentations of health information, as well as

independent access to health information. If we employ patient educators or *health infomediaries*, as I called them in my thesis, to provide health information, we free up clinicians to do what they are trained to do. At the same time we need to provide a community-based health education infrastructure which is both physical — like a community health library or an adapted telecentre — and virtual, such as an online health information access point. From my experience, desire for health information is universal; a fact supported by my surveys across low and high socioeconomic and university student groups.¹

Disseminating clinical information — from hospital to community structures

Beyond information sharing between health care workers and patients, we need a coordinated means of sharing important information among health care providers. Discharge summaries are becoming more commonplace in clinical practice in the public hospital system in Queensland. The Royal Brisbane and Women's Hospital and the Princess Alexandra Hospital both have their own versions. Yet even these, a vast improvement on what came before, have deficiencies. For example, neither hospital can access the other's electronic discharge summary records, and, while there is potential for these summaries to be emailed to GPs, they are largely inaccessible to emergency doctors or private clinicians, especially outside standard business hours. Yet these electronic discharge summaries provide a model of what can be produced.

Of course, a national electronic health record would provide a similar vehicle, with the advantages of being remotely accessible by clinicians at any time of day. Yet we have seen the difficulties in establishing such a product, with issues of privacy, security, database design and public acceptance. A national electronic record has been mooted for more than fifteen years, with little concrete progress. However, a centralised information database containing a

summary of a patient's health issues, accessible to clinical staff (only when providing clinical care), would greatly improve care and reduce errors. Such a database could also contain relevant *prescribed* health information packages which the patient could access and which could be added to and updated *regularly*. How do we pursue such a model? Should it be a private or public model — an opt in, fee for service model or a national system employed by public health services?

Why is such information sharing important? It is important because health care occurs on at least three levels: by and on behalf of the individual — that is, patients and their family members acting for their health; at the community service level — nursing homes and general practitioners who act to maintain health and treat conditions when possible in the community; and at the hospital, where accurate, objective evidence of current and past illnesses guides patient care. One of the most common complaints I hear from my colleagues is that people are referred to hospital unnecessarily for conditions which could be treated in the community. However, if community-based carers were provided with adequate information and thorough care plans, complete with recommendations for common occurrences, then inappropriate hospital admissions and the costs which go along with them could be reduced. Nursing home care in particular could be enhanced with the provision of such individualised care plans. One gentleman I know, a nursing home resident who has fairly stable, although progressive, heart failure, is admitted to hospital almost fortnightly for swelling and shortness of breath because of fluid overload (he loves his soft drink and drinks over 3.5 litres per day). This man has thirteen volumes to his chart (that is over a metre of stacked documentation!). Five days of hospital admission (and the resulting costs of approximately \$5000) could be avoided by a weekly GP visit in the nursing home and a specialist-approved care plan produced for the nursing home staff and GP.

Research as a junior doctor

These are some of the challenges I see in my everyday clinical practice. Yet solving them will neither be quick nor easy and will involve significant systems change supported by the evidence from relevant research. Unfortunately, several obstacles exist for system-related research in the hospital setting. In the public system there are too few doctors, and those who work in the system are too overwhelmed with clinical work to conduct research (especially in their “junior” training years). There is also little perceived benefit from investing in such research, especially in the private sector where remuneration does not extend to value-added services such as health education. Finally, the pursuit of further specialised training within medicine is not congruent with research; crucial accredited registrar positions are rarely available on a part-time basis, and a full time clinical load is too demanding to combine with any substantive research. It remains too much of an all-or-none proposition. Yet I firmly believe that we, as taxpayers, parents and children, want a better coordinated and integrated health system. The challenges are many, but the rewards are great.

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