JournalScan

Changing relationships between people and providers: making sense of patient centred health care

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In broad terms the development of policy seems to transcend national boundaries and health systems, at least in the developed world. For example, in England at present the emphasis is on "patient centred care" and, although this label may differ in other countries, some of its key elements will be recognisable elsewhere: aims to enhance the capacity of individuals for self-care; moving care out of hospitals and into communities in which patients live; and the development of care pathways that cross institutional and professional boundaries.

A common theme runs through these elements—namely, the changing relationship between people and providers. The word "people" is used because one of the questions we must ask is whether the traditional term "patient" should remain in use, given that some see within it an inherent inequality between "patient" and "provider". This question is central to the first paper written by researchers from Toronto.

Empowering patients

Is the term "patient" still appropriate when policy aims to place those seeking care on an equal footing with those delivering it? ► The literature shows that the terminology used to describe individuals who come into contact with health services is problematic. This is more the case in some care areas than others and in mental health, for example, "the historical power imbalance has led some to reject the term patient".

The paper contains an interesting discussion of the derivation of various terms. Although there is no explicit reference to deference in the term "patient", its Latin derivation means "to suffer". While traditionally understood as "an individual awaiting or under medical care and treatment", it can also be defined as "the capacity to tolerate delay, trouble or suffering without becoming angry or upset".

For those who seek health advice but are not ill, perhaps "patient" is not the best term. So what are the alternatives? Healthcare systems requiring people to pay for their care may encourage people to see themselves as consumers. But like "customer"—which comes from the Middle English word for tax collector and is defined as "one that purchases ..."—it implies that "medical services are commodities ... in a market". Another alternative, "client", comes from the Latin root meaning "dependent" and is variously understood as "one that is under the protection of another" or "a person who engages the professional advice or services of another". A further suggested alternative, "partner", comes from the Middle English word "partener" and is defined as "one that shares", "one associated with another", or "a member of a partnership". Although this term is not in wide use to refer to care recipients, it would seem compatible with the recent stress on shared decision making.

To test these terms, the researchers asked people for their views on six potential labels—"patient", "consumer", "customer", "client", "partner", and "survivor". Respondents attending four clinics—breast cancer (n=202), fracture (n=202), prostate cancer (n=202) and an HIV clinic (n=431)—were asked to express their views on a Likert scale ranging from "strongly like" to "strongly dislike".

All populations moderately liked the label "patient". No other label went beyond the indifferent range and most terms evoked negative scores in all four populations studies, with particular rejection of the terms "customer" and "consumer". The highest

approval for any label other than patient came from the HIV clinic in which about a third liked the term "client". Small groups among the HIV population liked the terms "survivor" and "partner", although more did not.

The researchers are keen to stress that their results should not be taken as an indication that people reject involvement in decision making but, at the micro level, argue that this label preference is appropriate: "sick individuals are indeed patients ... and our results accordingly cannot say whether otherwise healthy individuals ... might endorse [other] labels". They point out that the term "patient" tends to be moderately preferred, rather than achieving strong support. "The modern patient is no longer patient in the sense of waiting without complaint, or blindly following doctors' orders. Yet our results suggest that the individuals we surveyed still place a high value on a relationship with their providers that is based on a model other than that between buyer and seller".

Debate will no doubt continue as to how best to capture that relationship in a label.

▲ Deber R, Kraetschmer N, Urowitz S, et al. Patient, consumer, client or customer: what do people want to be called? *Health Expect* 2005;8:345-51

Can self-care health books reduce the amount of contact patients have with providers?

► More people are pointing to the potential of individuals to self-care to alleviate pressure on providers. The authors of this second paper hypothesise that "targeting patients with a comprehensive self-care health book given out with implied endorsement ... could successfully encourage patients to self-care". Their trial was designed to test changes in the duration or frequency of patient consultations due to the effects of being given one of [two] books.

The setting was a large general practice in St Albans, a prosperous area of southern England. 1967 recruits were allocated into one of three groups. The first group (n=660) was given the UK edition of the "Healthwise Handbook" (HW) which was developed in the USA and is used by Kaiser Permanente and other managed care organisations; the second group (n=659) was given the "NHS Direct Healthcare Guide" (NHSD), a book produced by an English health advice telephone line service; and the third group (n=648) received no book and acted as a control. People in the three groups were sent a questionnaire after 3 and 12 months. The results showed that those allocated a book were likely to have consulted it. In the first 3 months, 55% of those given the HW book and 42% of those given the NHSD book had consulted it at least once. Some 50% of those who did not consult their book in the first 3 months did so during the following 9 months. Those allocated to the control group were asked how many times they had consulted "any healthcare book", and about a quarter had.

Of those who had used a book, HW was seen as better for "understanding and ... knowing what to do". Those educated below "A" level (examinations typically taken at the age of 18 following a 2 year course from 16 that leads to university) were more likely to report that they found the HW information harder to understand than those whose qualifications were at or above "A" level. Conversely, those with education below "A" level standard found the NHSD book more useful. In both book groups about 57% at the two time points responded "more likely" to the question: "Did using the book make you more or less likely to try to deal with the problem yourself?"

The researchers examined consultation rates, the duration of consultations, and were supplied with data by NHS Direct on the number of calls from participants. The books did not reduce consultations. The researchers consider that this is surprising, and hypothesise that subsequent visits and calls were made "to obtain reassurance and confirmation about what they had done". Calls to the NHS Direct telephone advice service were more frequent among

those given the NHSD book, presumably because the service is recommended in the book.

Although the authors note that it is difficult to generalise results from research undertaken in such an affluent area with well educated participants, the findings imply that those who associate increasing self-care with decreasing use of health services may well be mistaken, at least in the short term until people develop the confidence not to seek confirmation of their reading of the textual information. But given the complexities and high risks involved in making judgements about one's own health, this confidence may not develop as quickly as proponents of self-care would wish.

▲ Platts A, Mitton R, Boniface D, *et al.* Can self-care health books affect amount of contact with the primary care health team. *Scand J Primary Health Care* 2005;23:142-8

Changing the balance of health care ► The five papers in this section look at different aspects of an international aim to change the balance of health care away from hospitals towards community based care.

A system dynamics view of shifting the balance of health care ► An English study (co-authored by a former health advisor to the current Prime Minister) takes a system dynamics approach to analysing the movement of services from one sector to another. System dynamics is a way of modelling the impact of change. It is mathematical but differs from simulation modelling. Broadly speaking, it is more qualitative, seeking to "understand and improve patterns of behaviour rather than produce point predictions".

The paper examines a case study of moving cardiac catheterisation services from a teaching hospital to district hospitals. While it is not the easiest paper to read, it offers some key insights into the ambition to move care from secondary to primary settings. The first insight is the importance of evaluating the consequences of a policy shift across whole systems rather than "isolated initiatives". The second is that shifting care can be a misleading notion. Tertiary care was still needed for complex cases and further investigation, even though secondary care services undertook the majority of low risk cases. The third insight is an important one for those who equate the shifting of services with the reduction of costs. Making services more accessible can increase demand without effort to control it.

The paper concludes that appreciating the wider consequences of shifting the balance of care is essential if services are to be improved overall. It recommends system dynamics as a way of helping to model and examine changes in behaviour.

▲ Taylor K, Dangerfield B, Le Grand J. Simulation analysis of the consequences of shifting the balance of health care: a system dynamics approach. *J Health Serv Res Policy* 2005;10:196-202

How do urban and rural dwellers differ in the health services they want? ► A study from Scotland, conducted as part of the 2002 Scottish Social Attitudes Survey which seeks to compare the opinions and attitudes of people living in different locations about access to and expectations of health services, was undertaken to inform consideration of access to health services in rural Scotland. 2108 adults were interviewed in urban settings and 930 in rural settings. These were conducted face to face and lasted around 45 minutes.

People in rural areas were more likely to be "very satisfied" with all health services than those in other locations. Those living in accessible small towns rather than rural areas were most likely to think a hospital was too far away. Respondents were provided with a list of potential improvements and asked to rank them. While cutting time to a GP appointment was most important for those in cities, other urban locations, small towns and "accessible urban" areas, it was one of the least important for those living in remote rural areas who prioritised quicker ambulance responses and free transport to hospital appointments.

Respondents were also given hypothetical illness scenarios which took place out of hours (defined as 18.00 to 08.00 hours in the UK). Those in remote areas were less likely than their urban counterparts to call an ambulance and were more likely to request a home visit from a GP for a potential heart attack in the night. There were similar patterns for other scenarios. While those in rural areas thought health services should be as good in rural areas as in urban areas, they define this in different ways with different views of who

will provide health services in emergency situations and out of hours.

The authors conclude that, in rural areas, generalists (GPs) currently have a role to play in substituting for emergency services. But as UK GPs are no longer required to provide out of hours care, "first contact provision is likely to move increasingly in the direction of Australian and US services where nurses ... are front line service providers". They recommend that their research is repeated periodically to reveal the extent to which rural health care is affected by service redesign, which will mean changes both in who provides services to rural people and where services are located.

▲ Farmer J, Hinds K, Richards, *et al.* Urban versus rural populations' views of health care in Scotland. *J Health Serv Res Policy* 2005;10:212-9

Seeing pathways as cultural cartographies: their shape depends upon who is doing the mapping ► A fascinating paper by English sociologists looks at care pathways as maps and is concerned with the process of their production. Its starting point is that "maps reflect and sustain [and by implication seek to shape] power relationships". The paper is concerned with a specific instance of map making in health policy—namely, the burgeoning use of care pathways. "From almost nowhere ... they appear to have become the tool of choice for ensuring ... quality of care, equity of treatment, optimal allocation of resources and a rational division of labour between healthcare professionals."

The study examines three primary care trusts (PCTs) in the Greater London area involved in the process of developing care pathways for patients with cataracts. Interviews were conducted over a period of 5 months with 25 health professionals and administrators (consultants, GPs, commissioning leads, public health doctors, nurse managers, and PCT board members). The interviews gave the researchers the opportunity to ask the key health professionals involved in the process to draw their maps, to reflect on them, and to articulate some of the assumptions that were built into them.

During discussion with professionals it became clear that "the more the maps aimed to furnish a precise, systematic representation of reality, the less true to life they became". A commissioning lead looking at one pathway observed: "Well I mean it's almost robotic. Ideally, I think they would just like to send the eye off and operate on the cataract and then send it back to the patient".

The authors argue that all of the pathways abstract the patient and reify the condition. Each depicts a simple idealised pathway for patients with cataracts with single "start and end" points, without turnings or crossroads or choice of routes. A discussion with a consultant is cited.

Doctor: The argument is that you're making it easier for the patient, you're wasting less time, but it really often is just to make the service more efficient so that you see more patients.

Researcher: So who are these pathways for?

Doctor: Well I think they are to try and speed things up for patients, but they really are to help the institution run more efficiently I think. They give the impression that they're very straightforward.

The researchers found little evidence that patients had either been involved or consulted on the process of pathway development. A figure in the paper allows the reader to contrast six different pathway models. The authors note that "what is immediately striking about these pathways is how different they are, particularly in respect of which profession occupies prime position". The pathways indicate territorial boundaries between professionals. For instance, maps (i) and (ii) exclude GPs altogether while maps (iv) and (v) relegate them to the margins of a world that is ophthalmology-centric. Maps (ii) and (iii) introduce new layers of expertise into the traditional mix of service (the "elite optometrist" and the "specialist ophthalmic nurse", respectively) who, not surprisingly perhaps, turn out to play central roles in the care pathways being proposed. The authors state that the pathways "furthered the sectional interests of their map makers without appearing to do so, enabling them to maintain the appearance of neutrality".

The paper sends a salutary warning that pathway development could fuel and be laden with interprofessional tensions. For example, in England pathways are rightly being held up as a way of planning care across institutions and better connecting secondary and primary care. However, in the context of shifting services out of hospitals, care must be taken that they are not used to exclude hospital doctors from primary care pathways nor by hospital doctors to minimise community input.

▲ Pinder R, Petchey R, Shaw S, *et al.* What's in a care pathway? Towards a cultural cartography of the new NHS. *Social Health Illness* 2005;27:759-79

The need to tailor the international approach of "case management" to local contexts ► An editorial in the *Journal of Health Services Research and Policy* notes that "chronic diseases are the commonest cause of death worldwide and their management has become one of the key challenges to health systems everywhere". England is piloting (in 10 areas) the American Evercare case management programme, targeting people over 65 years who have had two or more emergency admissions in the previous year. But, the authors ask, "how strong is the evidence in support of case management and what is its likely impact in England?"

A review of the interim evidence shows only weak evidence that case management reduces hospital admissions. The authors argue that the results may not be because such approaches are failing, but because we may fail to recognise their impact. They call for four changes: (1) effective mechanisms to identify high risk patients; (2) local arrangements for organizing and delivering case management; (3) a better understanding of the value attributed to improved quality of life; and (4) good studies of cost effectiveness.

The authors conclude that effective forms of case management are likely to vary across contexts, and evaluation needs to feed into "implementation and altered plans for a national roll out".

▲ Hutt R, Rosen R. A chronic case of mismanagement? *J Health Serv Res Policy* 2005;10:194-5

The critical contribution of primary care to health systems

► Few papers can have made a stronger or more impassioned case for strengthening primary care than Barbara Starfield *et al* in a recent *Milbank Quarterly* paper examining its contribution to the overall healthcare system. Its audience is clearly the American policy maker. "Although primary care came to be the cornerstone of the health services system in ... other countries, no comparable focus developed in the United States. Indeed, the formation of one after another specialty board in the early decades of the 20th century signalled the increasing specialization of the US physician workforce. ... We believe that the health of the US population will improve if this maldistribution is corrected."

According to the authors, the evidence suggests that (1) health is better in areas with more primary care physicians; (2) people who receive care from primary care physicians are healthier; and (3) the characteristics of primary care are associated with better health.

A 2003 study conducted in the state of Florida used cervical cancer mortality as the health outcome. Controlling for a variety of county level characteristics (percentages of whites, low educational level, median household income, percentage of married females, and urban/non-urban), each one per 10 000 population increase in the supply of family physicians was associated with a 20% lower mortality rate. The positive effect of primary care was also found in the significant relationship between reduced mortality and the supply of general internists, but not the supply of obstetrician-gynaecologists.

A study from Spain 10 years after a law was passed to strengthen primary care, which led to the establishment of a national programme of primary health care centres, found that death rates associated with hypertension and stroke fell most in those areas in which the reform was first implemented.

The authors point to six mechanisms that, alone and in combination, may account for the beneficial impact of primary care on population health: (1) greater access to needed services, (2) better quality of care, (3) a greater focus on prevention, (4) early

management of health problems, (5) the cumulative effect of the main primary care delivery characteristics, and (6) the role of primary care in reducing unnecessary and potentially harmful specialist care.

They conclude that "the relatively poor performance of the United States on major health indicators, despite per capita health care expenditures that are much higher than those of any other country, is a pressing concern for policy makers, the business community (which has, historically, paid for much of the health insurance in the country), and, ultimately, taxpayers. Efforts to improve the system to achieve better health at lower cost are rapidly becoming imperative. Primary care offers an effective and efficient approach to achieve that goal."

▲ Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. *Milbank Q* 2005;83:457-502.

Why does research so often fail to hit the mark and make a difference to practice?

The need for relationships between those who research and those who practice ► A paper from Canadian researchers offers a simple but important insight into why these communities often fail to engage meaningfully. It begins by noting that "there is increasing recognition of the need to ... transfer research findings from academic to practice and policy settings ... as researchers are challenged to disseminate research findings more effectively and policy makers and practitioners are urged to adopt evidence-based decision making processes".

The paper is based on the experience of a project set up to address the critical need for research to support the decision making of rural/northern regional health authorities (RHAs) by establishing a joint project group between them and the Canadian Institutes of Health Research. Interviews were held with members of the project committee and the CEOs of the participating health authorities as well as RHA staff (101 in total).

The paper confirms many issues identified in the literature, but also limitations on how these principles are commonly interpreted. The research suggests that the importance of personality has not received sufficient attention in knowledge transfer, and that lack of interest in research activities may not be the result of ignorance of the benefits of research (as is often assumed in the literature) but a response based on past interaction. Rather than significant differences in cultures between academic and practitioner communities (who are assumed to occupy different worlds), it may be a failure to develop authentic and respectful peer relationships that may better explain many of the barriers.

The authors stress the need to sustain researcher-practitioner relationships, but note that links at the individual level alone are not enough. It is difficult to move beyond individual learning—with collaboration enabling people to "do my job better" to the point where organisations start to make decisions differently. The next stage is to address barriers to the use of research at the organizational level within health authorities and research organisations.

▲ Bown S, Marten P. Demystifying knowledge translation: learning from the community. *J Health Serv Res Policy* 2005;10:203-11

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