

Perspectives on the expert patient

**Presentations from a seminar held at the
Royal Pharmaceutical Society of Great Britain
on 19th May 2003**

Policy
Development
Unit



**Royal
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of Great Britain

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The seminar was organised by the Royal Pharmaceutical Society's Policy Development Unit to explore the concept of the 'expert patient'. What is an expert patient? How can expert patients benefit other patients and professionals? How does the concept apply in the arena of pharmacy and medicines?

Six speakers set out a variety of perspectives on the 'expert patient' to an invited audience of senior government policy makers, professional bodies and patient organisations, followed by questions and discussion. The meeting was chaired by Annie Coppel, Chair of the Faculty of Prescribing and Medicines Management (College of Pharmacy Practice) and a director of the National Prescribing Centre.

The views expressed in this report are those of the authors and do not necessarily represent the policies of the Royal Pharmaceutical Society.

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The Royal Pharmaceutical Society of Great Britain is the regulatory and professional body for pharmacists in GB.

A commentary

Mike Bury

The speakers at the Royal Pharmaceutical Society (RPS) seminar raised a series of important questions concerning the history, development and future role of the 'expert patient' both as an arm of UK government policy, and as a feature of the changing social relations of health care. In order to focus the discussion here, three related points will be covered: first a comment on some of the 'drivers' behind the expert patient policy, and on some of the ambiguities they involve; second a comment on the patient's viewpoint of becoming an 'expert'; and third a broader comment on some of the assumptions and challenges involved in developing the 'expert patient' approach to health care.

What is driving 'the expert patient'?

Perhaps the first point to make in this connection is that the idea of the 'the expert patient' (as developed under the guidance of the UK Government's Chief Medical Officer [CMO], at least) can be seen as the latest in a line of policy initiatives emphasising the role of the patient in health care. In this sense it is not a new development, but an extension of existing approaches, which emphasise greater participation in health care by lay people and patients alike. The previous conservative government under Margaret Thatcher first explicitly championed a shift from a producer led to a consumer led health service. The idea of the patient as consumer was used as part of an arsenal of weapons to limit the demands and power of professionals in the health service, especially those of the medical profession. It was also linked to the development of the 'internal market' and competition within the National Health Service (NHS) in the UK.

In recent years a number of initiatives have been developed which include an increased role for the patient in the health care system, such as the Patient's Charter, Our Healthier Nation, Shifting the Balance, and the NHS plan published in 2000. Most recently the Commission for Patient and Public Involvement in Health has been set up to formalise the general approach. All of these moves, to one degree or another, embody the idea of a much more active patient, of a 'patient-centred' health care system, and a reduction in the relative power of professionals. For some commentators, they mark the end of paternalism and unquestioned medical dominance in the NHS (Coulter 1999, 2002; Smith 2002).

However, despite these powerful 'drivers', it is not entirely clear how far the government, or the Department of Health (DoH) wish to go outside of what might be seen as a circumscribed area such as chronic disease management. Speakers at the RPS seminar did not confine themselves to that topic alone. But tensions can often arise once patients or lay people express strong views. Recently, for example, lay people in Britain (in this case parents) expressed a preference for a particular approach to the vaccination of children, and the use of single injections instead of the MMR vaccine. Whilst there were undoubtedly mixed views among the public, some parents made their preference for three separate injections clearly known. However, the CMO, DoH and the vast majority of medical experts spent a great deal of time and effort blocking parental views and insisting that MMR was safe and acceptable. Although the argument about this issue continues, patient views, rightly or wrongly have not been allowed to prevail. It is clear from this and other examples that from a professional or political viewpoint, patient or lay views may be important and worth emphasising in the development of health policy, but are only likely to be allowed to influence practice under certain circumstances.

A crucial part of patient involvement in developing policy and health care delivery involves the issue of communication. The patient speakers at the RPS seminar mentioned, on a number of occasions, problems they or others had encountered in this area, implying that poor communication and information was a common barrier to developing 'patient expertise'. This is certainly a refrain which goes back through much social research on health care over the last few decades, very little of which has reflected well on the ability of practitioners to communicate effectively. Poor communication clearly hampers becoming an active patient, but what aspects of communication are being referred to here is not entirely clear. It is not, I think, simply a matter of better technical information (important though this is) or more of it, but that such information is tailored specifically to the particular circumstances of the patient. This means the professional listening to the patient as well as imparting information, and this is difficult to legislate for. It also has implications for resources, not the least of which is time. A redirection of some aspects of professional education will need to be part of the driving force in a new culture of shared communication, if patients' views are truly to count. Otherwise an official rhetoric will grow up emphasising patient involvement, and 'expertise', while down on the ground patients will remain passive recipients of professional care.

In addition to these factors, it needs to be noted that like patients, health care practitioners come in many shapes and sizes. Most importantly, professional agendas differ, and these can have powerful influences on the way policies are shaped and implemented, especially in the kind of political health care context that prevails in the UK. General practitioners, for example (through the Medical Practices Committee – www.doh.gov.uk/mpc/mpch.htm accessed 04/06/03) have been considering the implications of the changing character of health care, and the impact of a new 'skill-mix' in primary care, and have called for research on a range of issues before proceeding further. The 'expert patient' initiative is almost bound to get caught up in differing professional agendas, as each group faces up to the implications for its mode of practice, and the knock on effects of its relationship with other professional groups (Bury 2004). Many professionals will also see it, differentially, as part of the government's NHS 'modernisation' agenda. Community pharmacists, for example, may well be keen on seeing patients become more independent from their GPs. This might lead to a more direct relationship between the pharmacist and the patient, and an enhanced professional role for the former. GPs, on the other hand, may see this as threatening their professional territory and their traditional gatekeeper role to health care resources.

Speakers at the seminar also gave eloquent expression to the enormous capacity of lay people today to articulate their views and use the media to powerful effect. The use of the Internet alone is testament to what patients now have available, to use in their own way and in their own homes. As the sociologist Anthony Giddens has said, we live in a 'mediated' and 'contestable' culture (Giddens 1991) and this is just as true in health and health care, as it is in other areas of life. The virtual disappearance of the idea that technical and scientific knowledge should be the property of professionals, released reluctantly if at all, has now been finally swept away by mass information systems, including the Internet, but also by other means such as NHS Direct. Patients can now access the best information available about their health disorders, about treatments, and in the future about their doctors' performance. These developments are bound to become powerful elements in driving forward initiatives such as the 'expert patient', and a more patient led health care system more generally.

The patient's view

Whatever the forces are behind the 'expert patient', and however rhetorical not to say ideological some of its espousal may be, there are many positive aspects to the policy. In particular, there

appear to be clear attractions for many patients. This may take the form of becoming an 'expert patient' oneself, (100 pilot schemes are already underway in England, and more are planned for 2004-2007, Donaldson 2003) and then helping others, or by being able to consult such an 'expert' without having to see a professional at all. For some purposes, especially those of improving practical self-management skills this may have demonstrable benefits in terms of improving quality of life, though more independent research is needed to evaluate outcomes. The initiative is especially aimed at those living with chronic disorders (the CMO quotes a figure of 17.5 million such individuals in Great Britain in his original proposals) and should provide access to good information and advice from someone who knows what it is like to live with such a disorder. What is not known, however, is how acceptable or applicable such an initiative is to a wide range of patients - for example, of different ages, or ethnic backgrounds - and whether it will be seen (rightly or wrongly) as barring access to doctors.

At its best, the initiative offers the possibility for patients to be able to 're-colonise' their health, to use Arthur Frank's phrase (Frank 1995). Frank sees the development of active patients as part of a 'post colonial' era in late modern societies, in which the laity 'reclaims' illness from an erstwhile colonising medical profession. The era of medical dominance and patient passivity is seen, in this view, to be over, and patient advocacy allows the heterogeneity of experience to re-emerge. Chronic illness, here, becomes part of 'life's map' rather than an inevitably deleterious disruption of it. Although Frank is talking of patienthood in the North American context his precepts may be applicable to the 'expert patient' initiative in the UK, especially as is largely derived from a well established programme in chronic disease management at Stanford University in the US (www.stanford.edu/group/perc/cdsmp.html) (accessed 04/06/03).

Having said this, there are, however, a number of reservations that arguably need to be considered. The first is whether it is always in the patient's interest to 're-colonise' illness. Apart from the fact that patients may at times welcome having the responsibility of living with their illness lifted from their shoulders by a professional (a matter which the 'expert patient' approach does not by definition rule out) re-colonising illness may have a number of unintended consequences. It may not always be in the patient's interest to become an 'expert' in chronic disease and its management, especially if it means that life becomes preoccupied if not dominated by illness. It is true that the expert patient initiative has at its centre a view quite different from this. The idea is that patients should be 're-skilled' in order to manage their illness in such a way as to be able to get on with other valued areas of life. But becoming an 'expert' must run the risk that the most valued area of life will be the illness itself, and that being a patient will become a form of 'career', with life essentially revolving round the illness and its detail. Arthur Frank speaks of being 'successfully ill' without, perhaps, seeing clearly enough the ambiguity involved in such a notion.

More broadly, the boundaries between health and illness are now becoming so faint that Frank can also talk of the 'remission society' in which most if not all people will at some point in their lives (and perhaps quite early) live life 'in remission'. The CMO's figures for those living with chronic disease in Britain quoted above appear to confirm this. The lines between pathology and normality, between illness and health become eroded, as do those between health care professionals, and between professionals and patients. In this postmodern world of health and health care, the patient's experience may well come to the fore and gain clearer expression than ever. The emphasis on individual patient narratives in and outside medicine in recent years illustrates this point (Bury 2001). The 'expert patient' initiative embodies this in practice. In such circumstances attachments to the 'grand narratives' of science and medicine become problematic, as personal experience and 'life strategies' vie with the latest findings from science and technology.

However, such findings show no signs of taking a back seat to alternative ways of thinking about disease and its management. Tony Blair, for example, recently heralded a 'new era' in health care, this time through post genome diagnostics and therapeutics (White Paper 'Our Inheritance, Our Future – realising the potential of genetics in the NHS' Cm 5791, June 2003) with £50m of new investment. This is a far cry from the 'expert patient' initiative put forward by the CMO, and discussed at the RPS seminar, where 'low tech' life strategies are being discussed as the way forward in health care. Such mixed messages, of large scale investment in cutting edge science on the one hand, and a populist emphasis on the importance of lay views and lay experience in a newly fashioned NHS on the other, are difficult to reconcile. They seem to be pulling in opposite directions, though this may be more apparent than real if, for example, genetic information leads to individuals having preventive or therapeutic measures tailored to their personal circumstances. But this is, to say the least, a speculative matter at present. Whether the ambiguous and contradictory culture surrounding health and medicine today is conducive to addressing patients' needs in a coherent way requires careful consideration and further public discussion.

Assumptions and challenges of the expert patient

Given this backcloth, what then are the main challenges of the 'expert patient' policy as it develops? In some respects the policy may turn out to be simply a part of a range of initiatives currently occurring in primary care. In as much as 'expert patients' are trained, and then train others in chronic disease management, they may simply add another string to the primary care bow, and not much more. It is not difficult to imagine new forms of management of conditions such as arthritis and diabetes (already underway to some extent) which involve more active patients, and using alternative strategies to those available directly from doctors, without it representing a sea change in professional-patient relationships.

However, as the programme develops, and if it expands in ways that connect with the wider developments in health care and surrounding culture outlined above then some key issues are likely to emerge. Four present themselves as worthy of consideration. Space permits no more than a brief summary of these by way of a conclusion to this commentary.

First, while patients have a unique insight into their own experience, this is not the same as asserting that they are experts in matters medical. There is considerable sociological work on chronic illness which shows how knowledgeable people can become about their illnesses, but there is also work showing that patients and lay people can be quite ignorant about disease and medicine (see, for example, the recent discussion by Prior, 2003). This is of course, entirely understandable, given the range and breadth of medical science and its application to increasingly complex biological (let alone genetic) systems. Problems in medical knowledge become even more complex where notions of risk are involved, as they are frequently derived from epidemiological as well as clinical data. Differences between relative and absolute risk are an oft-quoted example. Skrabanek and McCormick make the point that the relative risk of airline pilots being involved in an air crash are probably at least a thousand times more than the average passenger, but neither should stop flying because the absolute risk for both is very low indeed. Numerous examples from medicine can be given (Skrabanek and McCormick 1998: 39).

A recent example can serve as an illustration of difficulties in the public discussion of risk. In late June 2003 it was announced by the British Medical Journal (27th June) that a 'once-a-day' pill could cut heart attacks by 80%. An editorial in the journal carried the headline, 'A cure for CHD?'. In press reports the meaning of the statistic given was, however, less than clear. The Guardian (27th June 2003), for example, ran an article on its front page stating that 'half of the population in Britain die or are seriously damaged by heart attacks and strokes'. It went on to say that the new

'Polypill' under discussion 'would give about a third of the over 55s an average extra 11 years of life free from a heart attack'. This population estimate seemed to be derived from an assumption of mass consumption of the pill. At the same time the paper added that 'the same effect could be obtained from eating a good diet loaded with fruit and vegetables, taking frequent exercise and giving up cigarettes'. Several different pieces of information from different sources were being combined here. The 'encoding' and 'decoding' of such messages (to use Stuart Hall's terms) is clearly complex, and it is difficult to imagine, in this instance at least, the reader coming away with a clear picture about this pill, its role in health promotion, or indeed its benefits.

Statistically based information, whether about risk, the benefits of treatment or of other matters is understandably beyond the ability of most patient fully to comprehend. Indeed, many practitioners may have the same difficulty. At the same time scientific data needs to be turned into a ready made form if it is to be used in everyday settings. Carefully conducted qualitative research has shown how patients may translate statistical information in this way, for example by turning figures on genetic risk in conditions such as Duchenne Muscular Dystrophy into categories (high or low) in order to make it manageable in terms of everyday decision making (Parsons and Atkinson 1992). Such creative tactics by patients do not sit easily in terms of either ignorance or expertise.

Second, there is the question of patient variability, mentioned earlier. The attractions of becoming or benefiting from an expert patient, as long as it is voluntary, may be, as has been argued, of considerable interest to a number of chronic disease sufferers. But others may prefer that health care professionals should get on and do what they are paid to do, namely to treat as effectively as possible and act on behalf of patients in securing the best possible resources and outcomes. It would be unfortunate indeed if the expert patient initiative began to be seen as a management tool to avoid expenditure on chronic disease, or reinforcing a view that specialist care is only appropriate for high-tech related conditions or life threatening illness. Variations in patients' views are important, as indeed are those of carers (which may not always be the same) and these need to be built in to the development of a truly 'patient based' service.

Third, whilst the expert patient initiative is largely directed at patients in primary care, less has been said about the implications for professional practice. The initiative not only has implications for disease management but also for the way professionals see patients and each other. This involves a major cultural change in professional outlook. If patients are to by-pass doctors in favour of either an expert patient, or a 'nonphysician clinician' as the Americans call them (nurse practitioners, therapists of varied stripes, community pharmacists, and other professional groups) then a less defensive culture will need to obtain in health care. While this may be in evidence in the competitive and corporatised environment of the US (McKinlay and Marceau 2001) pronouncements of professional groups in the UK to date do not give much ground for comfort. Mention has already been made of the response to a changing 'skill-mix' by sections of the medical profession. Changes in professional behaviour as much as among patients is part of the agenda here, but has received less attention than it might. Recent policy proposals such as that by the British Labour Party for a new 'patient contract' with their doctors only reinforce the point.

Finally, mention should be made of the question of selective uptake. Variations in patient views and preferences about the 'expert patient' also relate to who is likely to see benefit in the scheme and opt for such an approach. Whilst evidence from Australia was presented at the RPS seminar showing that such a programme was being adopted enthusiastically by specific 'socially excluded' groups, much of the evidence available on selective uptake of health promotion initiatives (if the 'expert patient' can be seen broadly as such) suggests caution. There is a strong and compelling argument that much health promotion carries a risk of increasing rather than decreasing health inequalities. The most obvious examples are those of smoking, diet and weight reduction.

Cigarette smoking and obesity are increasingly and strongly correlated with social class. Smoking has all but collapsed in middle class groups, but remains persistently high, at about forty per cent, among those from manual occupational backgrounds. It would be unfortunate indeed if the 'expert patient' initiative had the unintended consequence of adding another example of a health related initiative that proved attractive mainly to relatively young and middle aged white, middle class patients. There is no inexorable reason why this should be so – as those at the RPS seminar heard, and as has been recognised by other commentators (Kennedy 2003). But care in development and evaluation in practice are needed if the 'expert patient' initiative' is to be more than a passing fashion, only of interest to a small number of patients.

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Are we missing out on expert patients?

Lynn Faulds Wood

In a previous life I used to present the BBC's 'Watchdog' programme. In my current life I have become an expert patient. I am delighted to be here – in fact I'm delighted to be anywhere: I could easily be dead by now. It's great to be alive and with you. I am also glad to be here because this is my first opportunity to speak on anything to do with pharmacists, and I am a big fan – I think pharmacists are the third way.

The work you have all been doing on expert patients is fantastic. But I think the term needs to be widened out because there are so many of us who are experts and there are lots of ways we can help you and each other.

How many of you are patients or have been patients? How many of you were cancer patients? It's just me then. The only time I had previously been a patient was when I had my tonsils out. I had had a bit of rectal bleeding when my son was two. I went to the GP for a smear and I said "By the way, I have just seen some rectal bleeding. Should I worry about it?" He did a digital rectal examination, but he would have needed a jolly long finger to find my cancer. He said "Nothing to worry about at your age" (I was 41 at the time). So off I went, but something made me go back to the best GP in the practice and ask to be referred. But because nobody was worried about me it was nearly a year before I was actually diagnosed.

Until serious disease happens to us we tend not to think about what it's like being a patient. Just before I was diagnosed I looked fine but I was actually growing bowel cancer without knowing it. My son was three and I was about to have my life shattered. I didn't know for five years whether I was going to live to see my small son grow up. The cancer had actually spread through the bowel wall and into the lymph nodes. I was what was called stage C, though I hope you don't tell patients this. When I found out that on paper I had a 34 percent chance of survival, the hairs on the back of my neck stood up in fear and I didn't sleep for about a week. Patients often have a moment of fear that changes their lives forever. That was my moment of fear and it is why I am now spending most of my time being an 'expert patient'.

What is an expert patient? You are going to hear later on about people who help others manage chronic disease. I think the expert patient programme sounds absolutely great but I think first of all anyone who gets a serious disease is in a club that the rest of you don't understand. Plenty of you here today are from charities. Any cancer charities? Just one, and you are not a patient. I find that cancer charities are run by great people but very few of them have actually been patients. I speak a lot in Europe now and doctors there say to me "Why are you doing this? Didn't you just want to forget about your disease after you were cured?" Well no, actually; that moment of fear made me want to help others.

Another area where I think we are really missing out is patients as trainers of doctors and nurses. How do you as a doctor poke and prod people with serious arthritis, or other conditions that are extremely painful or physically difficult in other ways? Patient trainers could really help young doctors and nurses understand how to do this. The expert patient programme should be extended a bit further to include this. You have got patients with the most extraordinary expertise that can help you get where you want to go.

I opened a big conference recently in Birmingham and Manchester, the biggest cancer conference run so far by the Modernisation Agency. I was going to grill this woman who is a key service improvement lead for the country. But I ended up grilling her about becoming a breast cancer patient the previous year. The expertise she had gained as a patient was fantastic. I talked to her about every stage of her journey: the 17 visits to the GPs, with no blame, no rancour, no bitterness; just how it was for her. What was good; what was bad. Some people in the audience had actually been involved in her treatment but nobody felt offended by this because they all had a lot to learn. And I think it's probably all about how you tell them.

People like her, people at the top of the NHS who become patients, are Uniquely Informed Patients (UIPs). They have been helping to shape services and then suddenly they see services through other eyes, and it's a real eye-opener. I have now collected quite a few UIPs and I tell their stories. Another one, a doctor who was in a car crash, ended up in a different hospital to the one he works in, where he had a very poor experience. There was a lot to learn from talking him through the four days he spent there. If you want to get expert patients into the system, look for people who have this special knowledge: they have a lot to share.

When I finally reached the five-year all clear I made a TV programme called "Bobby Moore and me". Bobby and I were finally diagnosed by the same specialist at the same time, but Bobby had had four years of symptoms (I had had nearly a year). On his many visits to the doctor he had been told he had irritable bowel syndrome. Bobby, as you know, died; I survived. I got 28,000 letters after that programme and I decided to give up most TV work to do what I do now.

Because I used to present 'Watchdog', I liked to see evidence. I asked the doctors "Where is the research-based advice that let my doctors tell me I hadn't a problem?" And they said "Well, we know about the symptoms of bowel cancer but worldwide there isn't any research-based advice". So the first thing I did was help to get that with a fantastic doctor and his colleagues in Portsmouth. They created a database on 16,000 undiagnosed bowel patients. They were investigated and from the results came the world's first research based guide for bowel symptoms. The Department of Health subsequently adopted that advice. I produced a leaflet which the Minister launched about four years ago. We circulated one and a half million leaflets.

Another thing I helped with was looking at things like colonoscopy. Doctors learn how to do things by "See one, do one, teach one". I bet the pharmacists here learn in a very rigorous way but the doctors probably learnt a bit by osmosis on the way. Nurses learn in a much more methodical way. I have helped to set up national curriculum courses which are run from the Royal College of Surgeons' Department of Education. I've also helped to fund training centres in hospitals around the country.

Another thing I've been involved in setting up is patient feedback parties. Everywhere I went in the country, people were saying "We keep getting white middle class women with breast cancer coming forward to join our committees but we can't find bowel cancer patients". I'm not surprised: when I was diagnosed, if I told somebody I had bowel cancer they couldn't wait to get out of the room. Yet bowel cancer kills more people in this country than breast and cervical cancer put together.

To try and harness bowel cancer patients, I thought, well, we all like a good party, so we set up feedback parties in about a fifth of bowel cancer units. We worked with the Cancer Services Collaborative Patient Experience people. Whatever targets they were looking at, we looked at them as well. We tried to get the patients' parties to address about five areas: information, waits and delays, hospital environment, whether there were enough loos – all that kind of stuff – and

support. People came to the parties – 1500 bowel cancer patients and their partners came. Some parties were very small with about 20 people because they wanted to get really intensive feedback, while others had 350 people turn up at them. I went to nine. It was a fantastic snapshot of what was going on, and great feedback. You could say to them: “Hands up those of you who have had a barium enema”. At some parties a forest of hands would go up and in other ones you would hardly get any, so you could see this mismatch of resources going on right before your eyes.

We then pulled together as much of this material as we could and had a national event in London that brought together people from 35 of the parties. The Minister of Health, Hazel Blears, came too. She sat in every workshop, listened for about 20 minutes to everybody then she gave a half hour speech off the top of her head on what she was going to do about it. I thought that was quite remarkable for a Minister.

The patient feedback parties were regarded as being a great way for people to have a quick voice. I have also been going round the country talking to GPs. GPs have to talk to their patients now. Parties are a great way to get it done in one evening or one afternoon. GP surgeries are now inviting their patients to tell them what they think of the surgery. What about the environment – is our loo clean? Simple tips came out of the hospital parties (as well as complex ones) like leaving cleaning materials in the loo so patients can clean up after themselves if they have an accident – they don’t mind doing this.

The latest thing I have been doing is to work through the patient’s journey and come up with things we can share with other diseases as well. Five million people in any one year have got rectal bleeding. Another eight million have tummy upsets that go on for a bit. I don’t want to drive them all into your pharmacies or charity helplines. How can we sift them before they ever get to their GP? We have produced a symptoms leaflet to help with this. The idea is we trust people (they are not yet patients) with the best information about symptoms. We say to them it’s safe with bowel cancer to wait four or six weeks, but no more: see if you can influence the symptoms during that time. We spell out lots of ways you can try to do this, including going to your friendly neighbourhood pharmacist. I am really keen on people going and talking to pharmacists about their symptoms before they talk to their GPs, but it would be good to check whether the pharmacists are giving consistently good advice.

The thing we know about bowel cancer is that the symptoms are usually there day after day whatever you do. You may take a medicine that would temporarily make them go away but if they come back and are persistent you must go to your doctor. Chances are you won’t have bowel cancer but you must be investigated. I am glad to say the age thresholds for investigation are coming down. This is not an old man’s disease.

If you want to find patients, I have found that breakfast TV is a fantastic way of getting them. The first day we launched the symptoms leaflet we had 30,000 requests. Then I also set up a symptoms hotline: on the first day we had 156,000 calls. If you want to find expert patients or patients who have got particular expertise it’s very difficult to find the ones who are going to be really good. Television has been a great way to find them. I appealed on TV recently for HNPCC families, who have a particular predisposition to bowel cancer. They have been very difficult to find, but we had dozens of families respond to only two slots on TV.

Who would have thought in 1999 that I could get the Prince of Wales to say ‘bottoms’ on every single news broadcast? This is what he said:

“Now everyone I suspect knows somebody who has had bowel cancer, yet perhaps not all that surprisingly there is a real reluctance to talk about bowels and bottoms in this country. Not so long ago people wouldn't utter the word 'breast' in polite company. Now everyone talks about breast cancer and dealing with this disease is high on the national agenda.”

I also managed to get the Pope to talk about bowels and bottoms. That's what expert patients can do for you: we can just now and then get something like that to happen.

Why do I think we are missing out on expert patients? First of all, because you are not looking for us. People think patients don't want to talk about their disease. You can't shut me up about bowel cancer and there are plenty like me out there. You are often not adequately using us when you do get us involved on these little committees. You don't think about what we are going to do once we are on them. We get frustrated and bored and wander off again because you are not valuing us. Also, I have been speaking at conferences where the only people not paid are the patients – perhaps we need to think about recompensing the right patients some of the time.

Cancer Voices is an independent organisation with support from MacMillan. They have been fantastic at teaching patients how to feel they can get on with the health service. They have done great work - it can be very intimidating being a patient. When you go to conferences and you hear a great speaker who is a patient, chances are Cancer Voices will have helped them to be great. If you want to know more, do contact them.

And lastly, patients want to live and they want to help others live. We want to help all of you help us. So if I can help any of you I hope you know where to find me now. Thank you very much.

PS If you want to know anything about patient feedback packs or patient parties, please contact me and I will send you the templates we produced for bowel cancer.

Lynn Faulds Wood can be contacted at:
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The patient pharmacist

Nigel Simmons

Having been born with a congenital heart defect, and as a six-year old undergone surgery to repair a hole in the heart, I am certainly not unfamiliar with the healthcare system in the UK. The surgery left me with some residual aortic incompetence, whereby blood leaked back into the left ventricle after contraction. I had another inpatient episode due to endocarditis (an infected heart valve) about 10 years later which necessitated nearly 8 weeks in hospital receiving intravenous antibiotics. That admission led to my moving from being a routine patient, who took his condition and its limitations for granted, to an infant “expert patient” wanting to become a hospital pharmacist and be involved with drug therapy.

Moving on another 10 years, and my cardiologist decided that the time had come for the damaged valve to be replaced. Had this happened earlier, I would probably have needed a repeat procedure due to the infancy of the procedure and my then, small frame so the original caution was justified. As a result of the valve replacement I became a regular drug user, taking Warfarin every day and having regular blood tests to ensure the dosage was corrected when appropriate. Following the surgery I returned to work as before and despite residual enlargement of my left ventricle, caused by the additional work pushing against the leaking valve, led an acceptably normal life.

As my career developed, I was able to draw upon my own experiences to understand the patient’s perspective and see how the medical professions can sometimes overlook their patient’s needs for understanding and explanation.

In early 2001, I started a period of sick leave as a result of stress and depression. My GP prescribed an antidepressant, which I found very difficult to tolerate. I became almost zombie like; and feeling I was living in slow motion. Reducing the dosage seemed to have little effect; meanwhile I could see my weight ballooning, despite a lack of any interest in food. In desperation, I obtained an emergency appointment with another GP, who said that the rising weight and lethargy was attributable to something more than depression. I showed significant ascites (fluid-retention) and was told I needed to be seen by a hospital specialist as a matter of urgency.

Upon arriving in the A&E department at around 2pm, I was subjected to the usual preliminary investigations and after taking a case-history, the junior doctor called the duty consultant, who was well known to me (one advantage of working in a hospital!). After yet another examination, I was given the surprising news that I had developed congestive heart failure, which explained the fluid retention and other symptoms. I was told I would be admitted, and that as my cardiologist was in clinic on-site, he would probably come to see me. The cardiologist came just around 5pm, confirmed the diagnosis and without any beating about the bush, told me that the only long-term therapy would be a heart transplant! Fortunately I did not fall off the trolley with the shock, but I was certainly unprepared for the news.

After being fed an evening meal and allowed to relieve my needs, I was told around 9-10pm that I could now go to a ward, but needed a chest X-ray on the way. Then, just as I was about to be wheeled away, a nurse said she needed to give me an injection of Furosemide and promptly gave me an 80mg IV dose. This had an almost immediate effect, and having the X-ray and completing the journey to the ward was an uncomfortable experience. Why the injection could not have been given sooner was never explained, I was mobile enough to self-care and the delay meant a rather disturbed night.

Once my condition was stabilised, I was discharged with regular follow-up appointments with my GP and cardiologist. A few months later, I had another brief admission to hospital as a result of a racing pulse (tachycardia) which was brought under control by a bolus injection of Lidocaine, not a pleasant experience! This episode added another drug to my daily cocktail – Bumetanide, Digoxin, Losartan (widely used to treat heart failure, despite not being licensed for the condition), Spironolactone, Amiodarone and of course Warfarin.

Two years on, and my condition is clinically stable. I have learnt to live with the challenges of regular medication – planning my daily activities based on the effects of the drugs and hoping that friends and colleagues will understand. I have recognised that the formulation of some drugs ought to be reviewed – Metolazone an un-scored tablet most frequently prescribed as “Half a tablet...”; Losartan 25mg which are so small that they are difficult to pick up by anyone with swelling or numbness in the fingers. It has also become very apparent that clinical staff do not always see things from the patient’s perspective – not only the badly timed administration of a diuretic, but also the immediate presumption that the patient would be in favour of a heart transplant.

I still have concerns and fears: a recent poorly performed eye test lead to a suspicion of early diabetes; the persistent swelling / numbness in my toes seems also to be occurring occasionally in my fingers and whenever such problems occur, I am left worrying whether they are a symptom of disease, a side-effect of treatment or purely a state of mind.

Despite this, I intend to remain active and live independently. I know my condition will deteriorate in time, but whilst things remain stable life is there to be lived.

Of course I am not a particularly special patient despite being on slightly more familiar terms with those that care for me. Many other patients will suffer similar problems, but will be less able to discuss or understand them.

The Australian Sharing Health Care Program – Education for Clinicians and Consumers

Dr Malcolm W Battersby

Presentation Outline

1. Background to the Clinician Education Program
2. Development of a Generic Chronic Condition Self-Management Program
3. Six Principles Of Self-Management
4. Evaluation of The Partners in Health Pilot Self Management Program
5. National Sharing Health Care Education for Clinicians
6. Outcomes of the South Australian Self-Management Projects
 - 6.1 Eyre Peninsula Aboriginal Diabetes
 - 6.2 The Noarlunga Mental Health Program
7. State and National Implications for Self-Management Education

1. Background to the Clinician Education Program

The Flinders Self-Management Clinicians Education Program was based on the learnings of the SA HealthPlus Coordinated Care Trial 1979-1999. Coordinated Care Trials were national trials in each state instigated by the Council of Australian Governments (COAG) to develop models of care for people with chronic and complex illnesses based on the hypothesis “that coordinated care would improve health outcomes for the same or less cost”. SA HealthPlus was the largest of the nine national coordinated care trials based in South Australia in both metropolitan and rural areas recruiting 4,500 patients (3,000 intervention) based on eight projects.

The concepts behind the SA HealthPlus model of care was to provide:

- A patient centred approach (holistic);
- Behaviour change towards improved self-management;
- Use of evidence based guidelines;
- Prospective care planning
- Prevention focussed
- Improved coordination of care
- A focus on system change.

With a large range of community providers, hospitals and general practitioners a standardized model of assessment and care planning was required. This led to the establishment of the Coordinated Care Training Unit at Flinders University. During the trial the service coordinators received three days of training focusing on a problems and goals approach which was central to a self-management model of care and the care

planning and coordination approach. 275 general practitioners also received a three hour orientation and training in the concepts, processes and tools of the trial.

My involvement in the establishment of the Coordinated Care Trial was based on a behavioural approach derived from anxiety disorders, developed at the Maudsley Hospital and Institute of Psychiatry by Professor Issac Marks. In my training at the Maudsley Hospital I became aware of the motivational and outcomes based approach of a structured method to encourage patients to define their own problems and set achievable and measurable goals. It was anticipated that this model of care could be transferred from people with anxiety disorders to those with a range of chronic conditions.

Example Problem Statement

- Constant pain and discomfort leading to irritability and angry outbursts resulting in avoiding friends, family and doctors.

Example Goal Statement

- To use medication in prescribed way to assist me to spend 2 hours 3 times per week socializing with my family and friends outside of my home.

Goal Setting

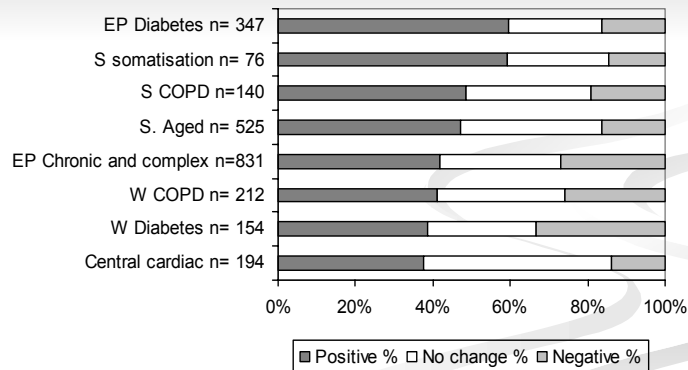
- The patient formulates a medium term goal which if achieved will reduce the impact of the problem
- The goal is described in observable measurable behaviour
- Progress towards achieving the goal is rated on a 0-8 scale

The independent local evaluation team analysed goal categories from the 3,000 patients in the intervention group and these featured a range of lifestyle issues such as exercise, diet, weight, smoking and alcohol, disease management such as control of diabetes and COPD and psychosocial goals in relation to social support, family issues and depression. A range of goals also included activities to improve quality of life such as hobbies, gardening, attending clubs and taking holidays.

Goal attainment was measured across the 3,000 intervention patients with between 40-60% of patients making some progress towards achieving goals. There was no change in goals for between 25-50% of patients and 30% were further from achieving their goals than at the beginning of the trial.

Achievement of Goal 1

Figure 2.15. Extent of Achievement of Goal 1 by project, end of trial.



At the mid stage at the Trial at 12 months a forum of service coordinators, general practitioners and trial managers revealed that the problems and goals approach was working well for many patients and significant medical and psychosocial changes had resulted. However, the major finding was that some patients did not require coordinated care because they were already good self managers. Patients who did benefit from coordinated care did so by becoming better self managers assisted by service coordinators. It was identified that whilst the aim of improving self-management was described in the original trial model, self-management had not been defined or operationalised. Additional learnings were:

- Self-management capacity is modulated by the illness and personal attributes as well as attributes of health providers and cultural and social factors;
- Self-management ability needs to be assessed before the right intervention is offered; and
- Not all consumers need self-management intervention and those who do will respond to a wide range of learning methods, some group, some individual.

2. Development of a Generic Chronic Condition Self-Management Program

A decision by Trial managers was made to develop and pilot a self-management program during the Trial. This included :

- Research and literature review;
- Focus groups with key stakeholders;
- GP education and engagement in the development of the processes and tools of the self-management program;

- Training of participants, the GP's, service coordinators and patients;
- A formal pilot project with evaluation.

After literature review and focus group exploration of the concept of self management the definition of self-management developed by the Centre for Advancement (1996) was adopted :

“self-management: involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes” (page 1).

In addition the definition also incorporated the findings of Kate Lorig (1993) that self-management is about enabling: “participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise to practice new health behaviours, and to maintain or gain emotional stability”.

3. Six Principles Of Self-Management

These definitions led to the adoption of 6 principles of self-management:

1. Know your condition.
2. Have active involvement in decision making with the GP or health workers.
3. Follow the care plan that is agreed upon with the GP and other health professionals.
4. Monitor symptoms associated with the condition(s) and Respond to, manage and cope with the symptoms.
5. Manage the physical, emotional and social impact of the condition(s) on your life.
6. Live a healthy lifestyle.

The self-management program was named “Partners in Health” and included the :

- Partners in Health scale
- Cue and Response interview
- Problem and Goals
- Care Plan
- “Partners” Handbook
- Symptom Action Plan (SAP)
- Monitoring Diary
- Doctor visit checklist

The Partners in Health scale was a clinical version of the six principles resulting in 12 clinical questions which a clinician or patient could ask of themselves in determining their capacity in each of the areas of self-management. The Cue and Response interview was a clinician administered interview initially created to validate the Partners in Health scale a patient rated instrument. Once the Partners in Health scale and the Cue and Response interview were completed the patients main problem and goal was and then elicited. The areas of self-management intervention and the problem and goal were then summarised on the care plan.

During the development of the program consumers requested a handbook to describe self-management and the role of the patient, GP, and service coordinator in the process. General Practitioners developed a generic symptom action plan and monitoring diary for patients and the patients who had been involved in the trial completed the tools by the addition of a doctor visit checklist.

4. Evaluation of The Partners in Health Pilot Self Management Program

22 patients, 13 GP's and 8 service coordinators were enrolled in the pilot program. After initial assessment and base line measures of the Partners in Health scale, patients were assessed three months later. The main purpose of the pilot program was to evaluate the clinical utility processes and tools of the program.

70% of patients felt better able to cope with life as a result of the program. 75% considered support by their GP's helped them to better manage their own care and 85% considered support offered by their service coordinators in the partners process "assisted them to manage their illness better". 75% of GP's stated that participation in the pilot program had influenced patients to manage their health "much better" or "better". 50% of GP's commented that they had changed their management of patients "very much" or "a little" (25%) as a result of participation in the pilot program.

The Coordinated Care Training Unit who managed the development of the pilot program, clinician leaders and trial managers came to the understanding that self-management should be seen as integral to chronic condition management. Chronic condition management involved :

- The patient;
- The family/carer;
- The clinician;
- The community;
- The health care system; and
- The provider organisation.

Principles of effective management of chronic conditions included collaboration between service providers and clients, a personalised written care plan, tailored self-management, scheduled followup, and monitoring of outcomes and encouragement of adherence to a treatment plan.

We have seen that collaboration between clinicians and patients was essential to the facilitation of self-management and more broadly the achievement of prevention and the management of chronic conditions. Collaboration involved :

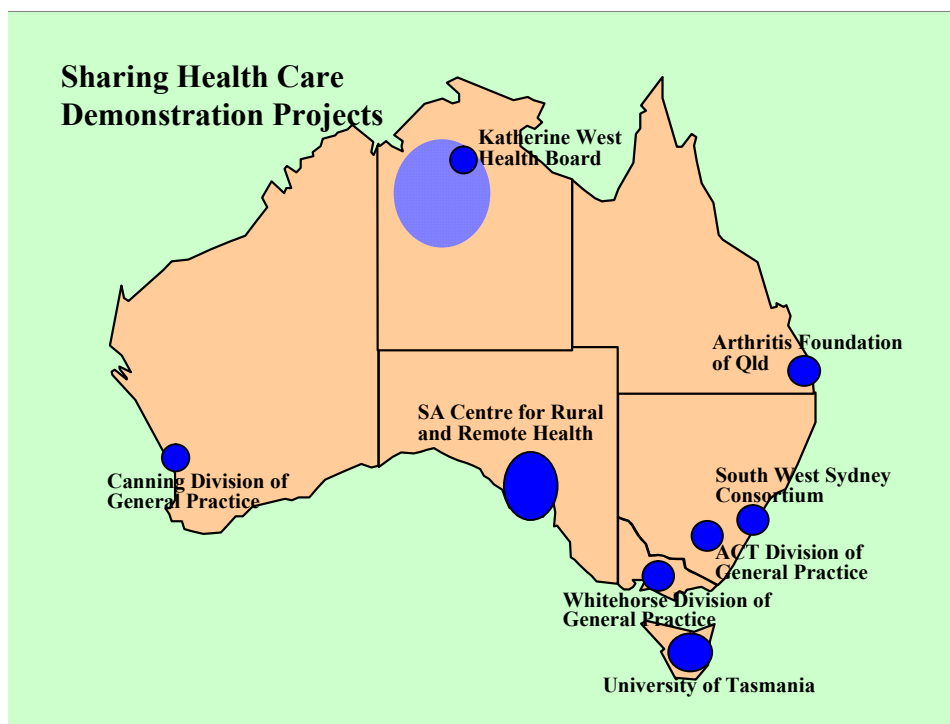
- Understanding of clients beliefs, wishes and circumstances;
- Understanding of family beliefs and needs;
- Collaborative identification of problems and goals;
- Negotiated agreed care plans with regular review; and
- Active followup.

Self-management itself was seen to be a partnership, based on an holistic (biopsychosocial) approach proactive, adaptive in problem solving and ultimately empowering to the patient.

During the pilot program it became apparent that the word self-management had many meanings, some of which created confusion amongst patients and clinicians. It was interpreted that self-management was “self treatment”, that it was a way of reducing the cost of care by reducing services, that visits to doctors were discouraged and ultimately that there was an increased risk of becoming unwell. It was decided therefore to adopt the term “Partners in Health” when describing self-management programs.

5. National Sharing Health Care Education for Clinicians

At the end of the Coordinated Care Trials the Population Health Branch of the Commonwealth Department of Health and Ageing established the National Sharing Health Care program. These programs aim to develop chronic condition self-management projects in each state and territory in Australia to develop models of self-management which could be applied across Australia. The Flinders University Human Behaviour & Health Research Unit (formerly Coordinated Care Training Unit) was funded to further develop the Partners in Health program as a clinician education course to complement the consumer programs being developed in each State and Territory.



Aboriginal medical services at Port August and Eyre Peninsula in South Australia, Katherine West and Danila Dilba in Northern Territory were included as part of the Sharing Health Care programs. The structure of aboriginal health services contrast with metropolitan health services where general practitioners work in a private capacity

funded through the Commonwealth medical benefits schedule system. Aboriginal medical services however are funded as a comprehensive service to employ general practitioners on a salary basis and are complemented by clinical nurses and aboriginal health workers. This has led to the trialling of adapted models of the Partners in Health program for each aboriginal community.

The formal education program has included a two day module aimed mainly at nurses and allied health professionals and a three hour overview for general practitioners. In addition, once practitioners have completed assessments and care planning a Train the Trainer program with accreditation is also provided.

An additional component of the education program has been the ability to trial the Partners in Health scale in a range of settings and populations to further validate the scale as a measure of self-management.

The National Sharing Health Care projects are developing models of care over three years; four of the eight projects are having as a primary intervention the Lorig, (Stanford) six week generic course. Projects are focussing on the national health priorities with comorbidities based around diabetes, cardiac disease, respiratory, arthritis and depression as a comorbidity. Each project aims to link general practitioners into self-management programs through the use of the enhanced primary care (EPC) item numbers specifically designed to facilitate chronic illness management by general practitioners. These item numbers enable payments of up to \$150.00 for assessment and care planning compared to the usual reimbursement of \$25-\$35.00 for an item of care. Projects aim to enrol between 300-500 patients over the three year period.

6. Outcomes of the South Australian Self-Management Projects

In addition to the National Sharing Health Care project, the Flinders Human Behaviour & Health Research Unit has been funded to provide clinician education to four self-management projects within South Australia. Two of these programs have recently concluded and have been evaluated:

6.1 Eyre Peninsula Aboriginal Diabetes

The aim of this project was to develop a chronic condition self-management program that is based on staff training, is culturally sensitive and flexible to promote self-management principles through goal setting, encourage lifestyle changes and improve access to preventative services.

This was a 12 month program which aimed to become sustainable through the use of the EPC item numbers which would pay for the additional assessment and care planning provided by aboriginal health workers and the general practitioner. The project was designed around a community development approach through the elders committee of the community. The program was based on two sites 400kms apart, one in Port Lincoln which is a rural community of 15,000 people and at Ceduna / Kooniba which has a scattered remote population of 500-600 aboriginal people. Extensive adaptation and development of the original Partners in Health tools and development of two training modules took place over the first three months. The training was separated into two

stages, the first self-management assessment and care planning and the second stage three months later of the problems and goals approach. Extensive support from the Flinders Human Behaviour & Health Research Unit was required during the development of the training program and for followup support. Two review workshops held during and at the end of the program provided a method of continuous improvement of the program.

The results of this project were that four aboriginal health workers were trained and 60 patients, 29 males, 31 females with a mean age of 46 were recruited. The elders prior to the beginning of the program identified four aims :

- A better understanding of diabetes;
- Better support of families and the community;
- More education of young people about diabetes; and
- More appropriate nutrition.

An evaluation of problems and goals at the end of the project show that the primary problems identified were living conditions, access to food, money and transport, family problems in relation to social obligation, crowding and alcohol. High levels of psychological morbidity were identified by patients as their primary problem such as post traumatic stress disorder and depression. Patients also identified their own lack of education and understanding of diabetes.

Quantitative outcomes included statistical improvements in all elements of the Partners in Health scale at 12 months. Problem rating improved significantly 6.22 -5.28 ($p < 0.01$). Lower scores indicate improvement in problem severity. Goal attainment improved from 7.26 to 5.42 ($p < 0.01$). Somewhat surprisingly in the short timeframe HbA1c improved significantly 8.74 to 8.01 ($p < 0.01$). Blood pressure improved slightly 139/84 to 136/83 (not significant). There was no change in the SF12 or Work and Social Adjustment scores with patients and aboriginal health workers describing significant difficulty with applicability and comprehension of the questions.

Issues identified by the project team included the time taken to provide the assessments but also the followup provision of services with some patients being at remote camp sites in the bush. A high priority was the identification of social and emotional and mental health problems through the problems and goals and self-management. It was identified that the support of the GP was critical not only in developing the care plans but supporting the role of the aboriginal health worker in the assessment process. The program enhanced the role of the aboriginal health worker and through the assessment and goal setting approach identified that trust had improved over time with their clients. Diabetes self-management assessment (PIH) was found to be simple, acceptable and useful.

The next stage is for the chronic condition self-management programs to be implemented throughout the system of care in both aboriginal communities and that a new round of training will involve all administrative staff and the social and emotional well being team in initial training so as to enhance the system wide approach to self-management.

6.2 The Noarlunga Mental Health Program

Noarlunga is an area in the southern part of metropolitan Adelaide with a regional population of 300,000 people. This program involved the Noarlunga Mental Health Service, the Southern Division of General Practice, the Flinders Medical Centre Division of Mental Health and the Southern Region Consumer Advisory Group. The aim of the program was to develop and trial a generic model of chronic condition self-management based on individual assessment, peer education and collaboration between mental health workers, GP's, patients and peer workers for patients with both mental and physical illness. The aim was to reduce risk behaviours and improve health outcomes over a 12 month period.

The model of care aimed to include both the Flinders clinician education program and the Lorig generic six week course delivered by peer educators. The developmental stage was challenging and complex with such an ambitious program to combine clinician education, assessment and care planning with a peer delivered generic course at the same time integrating both general practice and mental health services. There was initial resistance to a generic model from both health workers, and peer educators related to both the clinician education program and the generic Lorig six week course, however the project group decided to trial both methods without adaptation. GP training led to the development of a study group on self-management which became an education program about chronic and severe mental illness.

The results were that 21 GP's, 18 mental health workers and 7 peer educators received the Flinders clinician education program. 38 patients were recruited with the mean age of 42 (21-102) with 17 patients having schizophrenia, 7 depression, 5 bipolar disorder, 4 schizoaffective disorder, and 5 with anxiety and/or personality disorder.

21 patients attended the six week Lorig course.

Statistically there was a significant improvement on all items in the Partners in Health scale. Problem rating improved 5.19 to 3.16 ($p < 0.001$) and goal achievement from 5.35 to 3.55 ($p < 0.001$). The SF12 showed improvement on the mental summary score with no significant change on the physical summary score from baseline to six month followup.

Qualitative findings through focus groups showed that:

- The assessment process challenged mental health workers (and psychiatrists) perceptions of their patients' potential to improve;
- A structured assessment was initially time consuming but became quicker with practice and gave new information from the patients perspective;
- Peer educators emotional and physical health improved; and
- GP's learnt about mental health and became more comfortable in dealing with patients with chronic and disabling mental health conditions.

CASE STUDY

- 45 year old single man, living alone. Client of mental health service for 20 years with paranoid schizophrenia. History of violence (2 worker home visits), cigarette smoker, benzodiazepine dependent – doctor shopper, treatment order;
- Problems with planning, concentration, memory and problem solving, persistent paranoia;
- Goals: Better body image / decrease weight, decrease benzo's, better financial state, better care of self and dog.

As a result of this pilot program the mental health services have decided to establish self-management as part of core business. Strategic planning sessions and the establishment of a consumer self-management working party have led to a decision to fund peer educators as part of the mental health service. The program has led to the establishment and maintaining of links between general practitioners and mental health workers. Patients now have established physical care and a designated general practitioner.

7. State and National Implications for Self-Management Education

Through the experience of the Flinders Human Behaviour & Health Research Unit, both nationally and within South Australia the implications of providing an education program have been:

- Models for chronic disease management need to include self-management as a core component;
- It is essential to have clinician as well as patient education;
- Generic self-management programs are feasible, desirable and applicable in a wide range of settings and client populations;
- Education and training of clinicians acts as a vehicle for assisting change;
- Clinicians require follow-up support and supervision to achieve patient centred behavioural change skills and resultant attitude change in their ability to share in decision making with patients.

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The patient experience – how it can be changed

Robert Hallworth

Summary

Robert Hallworth is a pharmacist who has type 1 diabetes. He fervently believes in patient empowerment and adequate information provision by health care professionals. However, poor communication between professionals has resulted in a diminished patient experience for him on a number of occasions. He is a member of a Local Diabetes Service Advisory Group and has carried out appraisals of diabetes services on behalf of the NHS Centre for Healthcare Development (as a patient, not a professional). He will illustrate how patient involvement can identify methods to improve communication, with the aim of benefiting patient care. Pharmacists currently risk being excluded from these developments, to the detriment of the profession and patients alike.

Presentation

A few weeks ago it was my wedding anniversary and I decided to buy a new camera as a present for my wife, so one Saturday morning I set out to make a purchase. At the first store I entered there was no assistant available to advise me about the different models and I was told that he was on his break and would be back in 20 minutes, so I left. At the second establishment I was avidly pursued by several members of staff all keen to make a sale such that I wasn't given a moment to examine the different models or a brochure. Again, I decided I would be better making a purchase elsewhere. At the third shop I was allowed to look at leisure and provided with relevant advice however when I had made a decision I was informed that really I would need a case and an extra ultra violet lens together with spare batteries and film, which would have increased the cost considerably. I made my excuses and left. It was only at the fourth attempt that I had a pleasant customer experience with suitably attentive staff that were clearly not on commission to make a sale. As a result of this experience I know where I will be going to make a purchase in future.

In the retail sector we can always “vote with our feet” and go elsewhere, but sadly this is not the case with respect to healthcare.

Fred G. Meyer, the well-known American chain store founder said, “Always give the customer quality, value, selection and service.” With respect to the NHS we're all customers, but as health care professionals can we say that we always provide all these features to our patients (or service users)? I would vouch that we aspire to three of them, but selection (different ways of providing access to the service which may be more suitable for patients) is often not considered. How often do we ask patients “how it was for them”? Perhaps we should do so. Purchasing a camera can be stressful enough, but coping with a healthcare system designed entirely to the personal satisfaction of its component staff together with coping with a diagnosis of a potentially serious condition can do nothing to ensure a positive outcome for the individual.

Using patients to identify where communication is poor can be used to advantage. All patients have examples of poor communication which have adversely affected their experience of the healthcare system. Often the many professionals involved in their care don't seem to talk, as the same information has to be related to different health care professionals on several occasions. For example, I had been a hospital inpatient for four days when I was served my breakfast one morning, but there were no staff to be seen to provide my insulin injection (which I was perfectly

capable of administering myself) as the handover meeting was taking place in the ward office. After ten minutes, the meeting complete, the ward sister strode down the ward and as she passed me jokingly asked, "Aren't you eating your breakfast today, then?" "Not until I get my insulin", I replied. "Oh, you're diabetic are you?" was her reply.

Many professionals have received poor communication of the basics of diabetes care and are largely unaware of the condition and how to treat it effectively. This results in a degree of fear such that they remove insulin and blood glucose monitoring equipment from people with diabetes on the ward effectively "disabling" them in order to retain some degree of "control" of the patient. This seems a fairly ludicrous course of action, as the staff then have to ask the patient to show them how to carry out the blood glucose tests when they are due. A pressing need for diabetes education for nurses on general medical wards has been clearly highlighted by this situation.

Conflicting information presented to patients can be particularly disconcerting. Different health care professionals may provide different answers to the same question or offer differing advice. The patient is then left wondering which one to believe or, in fact, do none of them really know?

We move to primary care, where I receive all my diabetes care. My GP practice is very good providing annual reviews and screening and arranging blood tests a couple of weeks in advance so that results are available at the time of the clinic visit. However, I identified poor communication within the practice when trying to book an appointment for a fasting lipid test when the receptionist (fully aware I have diabetes) would offer an appointment no earlier than 10.45a.m. People with diabetes frequently require blood tests such as fasting lipids. It is important to ensure that these people are given the first appointment in the morning as they will have delayed their breakfast and also medication and may be more at risk of suffering a hypoglycaemic attack if they are kept waiting.

Providing patients with knowledge they can understand is enormously empowering as they have to cope themselves at 3a.m. when there is a crisis and no professional available. (Please be aware that if this is not done efficiently patients will improvise in a manner which may not be appropriate, as I shall relate in a few moments.) Relatives, partners and carers should be included in any education as they are often the people who cook the meals or may have to administer glucagon injections. Support at the time of diagnosis is very important as one of my local consultants estimates that when a person starts on insulin treatment he has to impart 47 separate pieces of information. Innovative approaches in the provision of information including a graded approach to prevent information overload are therefore important. Group and individual methods should both be available to address different learning styles and there are many examples of successful projects with the National Institute for Clinical Excellence (NICE) having recently provided guidance on education for people with diabetes. Use of a local "diabetes champion" may be a particularly useful approach as other service users are often better able to answer questions than health care professionals. For example, when I had my own community pharmacy people with diabetes came from a wide area with their prescriptions and problems because they knew I could answer their questions in a manner they could understand and I was aware of the problems of living with diabetes.

One recent well intentioned idea was initiated by a local consultant who began sending HbA1C and other monitoring results to patients which he felt was very forward thinking. He was thanked by one patient at a local meeting for being so open with his patients, but then told by the same person that she had absolutely no idea what all the figures and abbreviations meant.

A further local service redesign concerns evening foot screening sessions at my local hospital which have been arranged as a result of patients suggesting that easier parking and no need to take time off work would prove more convenient and increase attendance. A diabetes specialist nurse and dietitian will also be present at these clinics to provide information, advice and support as required and they will be evaluated for their effectiveness in eliminating non-attendance and suitability for patients. The idea is also popular with staff who value the opportunity to have time off in lieu during the day. Sometimes a little thought can be of value, because as Albert Einstein once said, "Imagination is more important than knowledge."

I have been privileged in the past to have been part of Diabetes Service Appraisal teams which have been invited to visit health districts under the auspices of the NHS Centre for Health Care Development to interview relevant health professionals and service users about the diabetes service and make recommendations for possible improvements. These are then addressed by the relevant PCT and hospital Trusts in order to optimise the patient experience. The visiting team usually comprises a public health doctor, podiatrist, GP, service user, carer, consultant physician, primary care manager, dietitian, diabetes specialist nurse, practice nurse and optometrist. There is usually no pharmacist included and I have been present as a service user. We have found examples of good practice (and also not so good practice on occasions).

In one of these areas I encountered my example of patients making their own decisions despite health care professionals mentioned earlier. We visited the local diabetes nurses who were very poor at patient empowerment. They told us that they only allowed two of their patients to adjust their insulin doses because the others were not really capable of doing so without their help. All the other patients had been told to phone the nurses first before making any changes. Our next visit was to meet a group of service users and so we asked them about insulin dose changes. They told us that because the nurses wouldn't show them how to do this and were hard to contact by phone that they adjusted doses themselves based upon experience and information from other patients, books or the internet. However, we did witness some very enlightened use of good communication. In one district the diabetes register was used for more than data collection and operation of a call and recall system. It has been utilised to send regular updates to patients concerning withdrawal of certain brands of insulin or the availability of new items on prescription such as pen needles. An associated website providing details about diabetes with a local flavour is currently being developed. In a totally different area one GP practice was helping with the support and information needs of their patients by paying for the first year's subscription to Diabetes UK for all people newly diagnosed with diabetes.

I am also a member of my Local Diabetes Service Advisory Group (LDSAG), a multi-disciplinary group facilitated by the Primary Care Trust (PCT) to promote co-ordinated care of people with diabetes locally. LDSAGs are usually composed of:

- Representatives of specialist diabetes teams and primary healthcare teams
- People with diabetes
- Commissioners of diabetes services (PCTs)
- Consultants in Public Health medicine
- Managers of service providers (e.g. community nurses)
- Representatives of local Diabetes UK groups
- Representatives from black and minority ethnic groups
- and also where necessary social services, education, health promotion and voluntary group representatives.

Significantly, once more, there is no pharmacist as I am present as a service user.

One recent problem involving discharge medication, which I am sure is fairly widespread, was identified and solved by one of the patient representatives. It was noted that, "Communication of prescription requirements, especially for needles and blood glucose strips, and accurate production of repeat prescriptions by GP practices seems to be a universal problem. Prescriptions are often inaccurate, or practice staff cannot find the exact items on their computer." Would better training of practice staff be the answer? The LDSAG was about to discuss the issue when one patient said, "Rather than use a brand name that they have trouble with couldn't we use a code?" Thus was born the system we have used for the past 9 months of Read coding all the discharge data which I have helped set up with the diabetes nurses and which has largely solved this communication problem.

You will note that I highlighted the absence of pharmaceutical representation on the two above groups. This is strange since community pharmacists are the most accessible healthcare professional and are encountered more than any other healthcare professional by people with diabetes but are not seen as part of the care team in many cases. I'm sure my local diabetes nurses and podiatrists won't mind me pointing out that due to pressure of work you can only access their service via an answer phone and it may take up to 48 hours to receive a reply.

Pharmacists must communicate better with patients. In common with many GPs I think they do not like to intervene and attempt to assist patients using insulin. Since I sold my pharmacy around 2 years ago I have obtained my prescription from other pharmacies and I have ensured that my wife or another family member always collects it. We have never visited the same pharmacy more than twice and have used independents and multiples, but despite the fact that this prescription represents a new patient with diabetes using their pharmacy nobody has ever asked if we were familiar with the medication and able to use it correctly.

Standard 3 of the Diabetes National Service Framework (NSF) concerns patient empowerment. Pharmacists can assist with this easily by advising how often blood glucose measurements should be carried out, their significance and importantly assist in quality control of the meters, because any patient using an incorrectly calibrated meter is not empowered to manage their condition well.

Finally, do pharmacists seek service users' views? They should do so as an important component of clinical governance. It is particularly important to open this and other communication channels to become a fully-fledged member of the diabetes network espoused in the NSF Delivery Strategy. To use an aviation analogy pharmacy is currently the 'missing man' in the diabetes care formation.

A further development mentioned in the NSF is the integrated care plan which if it is to work properly requires good communication at all times in particular with the patient. I hope that I have provided some examples of where the utilisation of patient experience can help to improve services to the benefit of patients and professionals and will give all health professionals the enthusiasm to utilise the Expert Patient. To illustrate this I would like to finish with a quote from Vincent van Gogh: "What would life be like if we had no courage to attempt anything?"

Can expert patients be created?

F Roy Jones

Introduction

Expert patients might be defined as people who understand that the quality of their lives is primarily up to them; believe they can exert significant control over their own lives; are determined to live a healthy life despite their chronic condition; are realistic about the impact of their disease; and have worked out what services exist and how they can be accessed. These phrases bring together some of the key ideas used to describe an expert patient. While anybody involved with 'expert' or 'self-managing' patients would recognise these as key elements in a working definition, the sentences are somewhat arid and don't pick up just how much fun is actually involved in the self-management courses that involve a process of personal change.

History overview

Self-management courses as we know them today began at Stanford in 1979-1981 as part of Kate Lorig's work for her doctorate in public health. This origin in public health is significant, as I believe is Kate's practical background in nursing. The initial course in arthritis (the Arthritis Self-Management Course, ASMC) initially took off because of the interest taken by the Arthritis Foundations in America, Australia and New Zealand and was boosted when the research was published in 1983. Curiously, only in the area around Stanford University, Palo Alto, where the ASMC was originally trialled, did the idea persist that these courses were best user-led. Throughout the world it is rare for the ASMC to be delivered as a user-led patient education intervention except now in England.

In the 1990s Arthritis Care (where I was then a director) began to work on the ASMC and, perhaps because we were a voluntary organisation, we warmly espoused the idea that people with arthritis were a resource of problem solving skill in the community and could learn to teach the course. (Lynn Faulds Wood described them earlier as 'uniquely informed patients'.) We renamed the course *Challenging Arthritis*. Volunteer tutors were recruited, often through open advertisement, and some of these really wonderful people are still working for Arthritis Care, the Expert Patient Programme or similar initiatives.

Those of us who were busy organising *Challenging Arthritis* were shaken when in the mid 1990s we discovered what was happening at Stanford. They had recognised that most of the content of the ASMC was not specific to arthritis. Rather, it had general application and a course for people with chronic conditions was being trialled. For a while we didn't know quite what that was going to mean for Arthritis Care. Eventually the Long Term Medical Conditions Alliance, LMCA, set up the Long-term Illness Project, (known affectionately as Lill) and Arthritis Care provided the training and know-how. The first Stanford-based chronic disease self-management courses in the UK were delivered by nine member organisations of the LMCA.

In 1999 came *Saving Lives: Our Healthier Nation*¹ and it cited Arthritis Care's *Challenging Arthritis* as an example of good practice. It took us two days to read on and discover that what the Chief Medical Officer was interested in wasn't the work on arthritis so much as the potential of the chronic disease self-management course. It was to be a route for the development of expert patient skills in chronic disease. In October 2001 the *Expert Patient* report² was published and soon afterwards an implementation group was formed. In 2002, 65 full time training staff for the *Expert Patient* programme were recruited. In May 2003 they met at Aston University to celebrate their first year. All of these, including the principal trainers, are suitably qualified people successfully managing lives with chronic conditions. Their role is to demonstrate what these courses can offer to Primary Care Trusts in England by training (volunteer) course tutors to deliver at least 4 courses in every PCT.

About self-management courses

The content can be summarised as follows:

- Principles of self-management
- Exercise, relaxation
- **Problem solving, goal setting, contracting**
- Cognitive symptom management, challenging negative thinking
- Dealing with strong feelings: anger, fear, frustration, depression
- Fatigue and pain management
- Eating well
- Communication with health professionals and family
- Medication

The problem solving line is emboldened because it has caused some controversy. When in 1993 we asked our rheumatology friends why they hadn't worked with the Stanford course in the UK, it was because it was too American. British people wouldn't like it. In particular they wouldn't like 'contracting', as it was then called. (It is now termed 'goal setting'.)

This part of the course process occurs at the end of each six weekly class meeting. Participants and Course Tutors alike identify what they going to do for the next week to take a bit more control over their lives with their chronic disease(s). Do notice the construction of that sentence: '...a bit more control over their lives with...'. It's not more control over the disease or a symptom, it is a bit more control over 'life with'. As people identify what they are going to attempt, the tutor checks that it is both attainable and a modest challenge. The object is to push the boundaries and to discover that this is possible.

Early in the next meeting successes and failures are reviewed. This is often a very moving and sometimes a funny part of these classes. Sometimes participants have done infinitely more than they ever thought they could. Sometimes they have actually just managed to achieve their goal; very occasionally they haven't made it this week but are pretty sure they will next. We can now say on the basis of the research and a decade of practice, without fear of contradiction, that this course element is something that people appreciate and enjoy. One of the Scottish Arthritis Care self-management trainers commented,

BT tells you
'It is good to talk'
Self management
'Learns you to laugh'.

¹ *Saving Lives: Our Healthier Nation* (1999). White Paper, Department of Health, England

²,(2001)., Department of Health, England

We also know now that it is a key part of a social learning process.

The outcomes mystery

In the early days in Stanford there was a mystery: why does the ASMC work? It was clear that it did: standard research instruments had been used to identify changes in

- Anxiety (reduction)
- Depression (reduction)
- Pain (reduction in the arthritis course)
- Fatigue (reduction)
- Health status (improved)
- Utilisation of health resources
 - visits to the physician (reduction)
 - visits to emergency room (reduction).

Furthermore, these changes were sustained over four years without further intervention or support.

The question was ‘Why?’ As research continued it gradually emerged that positive outcomes could not be explained by knowledge, sharing, use of self-management techniques, or even behaviour. Thus began a search reminiscent of the pharmaceutical quests for the key molecule in an established medicine that has been generally prescribed for 50 years. What was it that actually made the difference? What was eventually found to correlate was a change in self-efficacy.

Self-efficacy

This term needs to be introduced carefully to a British audience. It is part of a wider concept of social learning but has taken on a life of its own, accumulating a substantial body of research.³ It is not well understood in the UK medical context although familiar in education and in social studies. One of the important points about the concept is that self-efficacy theory “diverges from the prevalent cognitivism”. Cognitivism is the assumption that by providing information (e.g. to help someone respond effectively to an experience such as the onset of chronic disease) a professional responsibility has been discharged. Cognitivism is evident in phrases such as ‘the informed patient is the empowered patient’. That’s cognitivism and it is not true. While knowledge is an essential tool of the self-efficacious person/patient, it is not in itself empowering.

Here’s an illustration: in the film *The Graduate*, Dustin Hoffman is given a 21st birthday gift. It turns out to be a scuba diving set. He puts it on and waddles out through the dining room towards the swimming pool. He is fully equipped and yet totally disempowered. DeClemente⁴ has suggested if you overload people with information when they don’t believe they can use it, they will even avoid any preventative actions they might take to their benefit.

Self-efficacy theory asserts that knowledge only has intrinsic value in a context, i.e. when it can be utilised. If the context is one in which I am going to be able to look after myself better and I can use that knowledge, that knowledge is seriously useful, but don’t give me knowledge I can’t use, (even if, doctor, you find it fascinating in your context!.)

³ See Bandura A (1997). *Self-Efficacy: the Exercise of Control*, Freeman and Co

If you want to look up self-efficacy on the net then this is a good place to start:

www.emory.edu/EDUCATION/mfp/effpage.html

This is the Emory College, Atlanta, website and it has a number of pictures and a useful essay. I particularly like the first picture that comes up. It shows a 'Little League' baseball player. He's maybe 6 years old and he is the pitcher. He has got to make the pitch to save the game. There is sheer determination in the boy's face and he has a cunning grip of the ball that he's concealing from the striker by holding it behind his back. He has worked out exactly what kind of a pitch he is going to make. The picture gives you a really strong idea of how *self-efficacious* this lad is. The words beside the photo are very formal and academic but it is the boy's face that tells you what they mean. "Self-efficacy is the belief in one's capacities to organise and execute the sources of action required to manage prospective situations".

Our self-efficacy influences the choices we make, the effort we put forth, how long we persist and how we feel about things. Somebody with a long-term condition who is feeling its impact may well go through a process of restructuring his/her beliefs about, "How do I work with this new circumstance?" Confidence is built on learning from peers who are functioning well. New skills may have to be learnt. New goals need to be set. And there are people who are my models who are being successful. Lynn Faulds Wood picked up so many of these points earlier. However, it is important to note that if any of these aspects are missing, then the factors that make for self-efficacy are reduced. It should also be remembered that it is easy to shatter someone's confidence and to lose self-efficacy. Both Robert Hallworth and Nigel Simmons indicated in their presentations just how easy that can be.

Doctors and pharmacists

If you were someone who had just done one of these self-management courses how would you look back over the six weeks?

- You might feel you had rediscovered your own resourcefulness
- You might know you are able to redefine your roles in your family
- You might be determined to make better use of your local health and other community services
- You might be taking life less seriously and laughing more.

This is how I observe participants feeling and behaving. It is wonderful to rediscover that you are resourceful; that there are things you can do for your family you didn't know you could do; that there are all sorts of resources in the world around you that allow you to manage your life effectively and actually have fun with people. Those are important and powerful things, and a person feeling and doing them feels better. Now a doctor might ask "But are they really better?" And when they say that, a popular confusion is revealed. Disease process is being mistaken for personal progress. It seems to me that an over-emphasis on disease progression often makes life difficult for healthcare professionals. Lorig's and Bandura's work strongly suggests that we must separate studies of disease process from research such as that on self-efficacy that looks at how people live successfully with or despite their disease.

So where does this take us in terms of pharmacy and general practice? From the work around concordance we know that enabling patients to make good quality decisions has become central. And we also know from that process that medicines are a resource; a resource with potentials and

limits. At a Medical Research Council meeting a few weeks ago a group of us looking at the possible agenda for the MRC's work on Complementary and Alternative Medicines took a straw vote on whether we thought overall that medicines, on balance, improved or made things worse for people. It was about 50/50 with a couple of very senior people reckoning that on balance the medicines made things worse. Only about half the meeting actually reckoned they made them better. The ready assumption that medicines are the answer to illness is being challenged. Clearly, medicines need to be understood by people and doctors as key resources.

Little by little the prevalence of cognitivism is being confronted. All too often it has been an excuse for inaction. We need a better understanding of how people learn from professional advisors (doctors, pharmacists and other health professionals); and consequently how to prescribe effectively.

There seems to be a movement underway in the areas that Malcolm Battersby and other speakers have indicated for us. The emergence of the idea of the expert patient is actually an opportunity for re-skilling. The courses re-skill the patients. We also need to be re-skilling pharmacists, doctors and health professionals. We know that the best outcomes come from effective patient/health professional partnerships. These need to be built.

Where are self-management programmes now?

In addition to the 65 staff trainers, 230 volunteer course tutors have been trained (of the target of 606 needed by April 2004). 209 of the planned 1212 courses for the project phase have been conducted. And approximately 2,300 people have completed the course towards a target of 15,000.

Anne Kennedy in Professor Ann Roger's Unit at the NHS Centre for Primary Care R&D in Manchester is leading the research. York and Bristol Universities are also involved.

The voluntary sector providers have been in something of a limbo while the *Expert Patient* programme has been getting underway. But they are significant providers of self management courses. Arthritis Care provides a considerable number of courses and LMCA's member organisations are also yielding about 800 course completers a year.

We now have examples of growing partnerships with the LMCA and its Self-Management Network (SMN). The SMN will work more closely with the *Expert Patient* programme. There are other powerful drivers for user-led care.. Guidance on Section 11 (of the NHS Plan) calls for much more lay involvement. A cultural change is underway that might over time remodel the prescriber/patient relationship. This needs to be more widely promoted.

A key bonus coming out of these programmes is that some people wish to be more involved and to make further use of their self-management capacities. They seek opportunities to help people like themselves. Naturally, not everyone will want to be engaged with health and social services but there are many other opportunities in the community. So why should these be supported? There are probably three reasons:-

- Benefits for people: being socially active is good for society and good for individuals
- The possibility of reducing the demand on GP time: people who are focussed on living rather than disease may well make better use of services
- The impact of new technologies in the modernisation agenda: self-management in the sense described here is well known but not integrated into services.

This is so close to the Public and Patient Involvement agenda that it sometimes feels as if these possibilities are driving the programme ahead.

Professor David Taylor⁵ and I and two other colleagues have addressed some of these issues in *Future Partnerships*.⁶ We have identified the potential and some of the problems. The importance of self-management as a driver for modernising primary care provision has not been recognised here in the way it has been by our Australian colleagues. This may be because in England the roll-out costs so little that it has not come to the attention of PCT Chief Executives.

New legislation around Patient and Public Involvement, Section 11 guidance and the government's *Compact with the Voluntary Sector* require PCTs, local authorities and all the other relevant agencies to develop partnership working agreements. This is new territory for many and there is a lot to learn.

Conclusions

So can expert patients be created? I seriously doubt it. I think there are many, many people who can be encouraged and supported who would choose the pathway towards being an expert patient/active self-manager rather than the opting for the alternative of learned helplessness. Self-management programmes offer an alternative to becoming increasingly dependent and passive: faced with that choice, most of us would prefer to take the active route.

⁵ Of the London School of Pharmacy.

⁶ Jafri, Jones, Taylor and Wakeling (2003). *Future Partnerships: Primary Care in 2020*. Department of Practice and Policy, The School of Pharmacy, University of London. Available on request from Professor David G Taylor at david.taylor@ulsop.ac.uk