

Partnership working and new roles and responsibilities

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ABSTRACT

However you choose to define partnership working, it comes down to the changing relationship between patients and physicians. We're unlikely to see a sudden step change in patient behaviour but the degree of change for some physicians should not be underestimated. *Montgomery* has shone a spotlight on the cultural shift that lies at the heart of partnership working and, with it, a reminder of how challenging it is to communicate risk. Learning from the legal services sector reinforces the importance of this in the evolving role of the professional. Partnership working fundamentally comes down to the ability, skills and capacity to have a conversation. Better information has set a new framework for the conversation but, while essential for partnership, it is not a panacea. A conversation is needed in which a patient's thoughts, concerns and their preferences are placed equally alongside the clinician's expertise, experience and skills.

KEYWORDS: Partnership working, shared decision making, ethics, Montgomery, risk and communication

Introduction

As a lay person, ethics can feel dangerous territory to step into. What does 'ethics' mean from a patient perspective? Is it different to what it means to professionals?

It can be easy to think of ethics as the preserve of moral philosophers, professional regulators or formally convened ethics committees. As consumers, we're increasingly familiar with ethically sourced produce but healthcare is very much a service, not a product. And how legitimate is it to compare healthcare with any other service where we may be more of a consumer and less of a user or beneficiary?

At its simplest, ethics is a system of moral principles affecting how people make decisions and live their lives. So if partnership working is about shared decision making then it is of course inherently about ethics too. Some of the recent debate around partnership working between patients and physicians has, therefore, inevitably raised questions of ethics. It is right that these questions are considered from both the patient and physician perspective. In addition, the *Montgomery* decision¹ has re-raised questions about risk and

communication; two issues which arguably lie at the heart of partnership working.

Against this background this article aims to answer the following questions:

- > Will a new partnership between patients and physicians lead to more conflicts and disagreements?
- > Will this create a new set of ethical tensions or issues? Are there inevitably new ethical issues arising from shared decision making?
- > What, if anything, can we learn from other sectors?

Understanding the concept

Partnership working – patient-centred care – person-centred care – whole person-centred care – shared decision making – self-management support. There is no shortage of concepts and terms, many of which then require further definitions in turn; the danger is that different people mean different things by them.

However you choose to define partnership, it comes down to the relationship between the physician and the patient. What is clear is that, like it or not, this relationship is changing.

In considering long-term conditions, this is not new. The original Expert Patient Programme (Box 1)² was based on feedback from GPs caring for people with chronic conditions, and who had identified that the patient often understands the condition better than they do.

Notably, at the core of this definition is a two-way process. For example, the expectation is that the patient communicates effectively with the professional just as much as the professional communicates effectively with the patient. Perhaps this is why, more recently, partnership working has

Box 1. Expert Patient Programme.

The Expert Patient Programme defines an expert patient as someone who:

- > feels confident and in control of their life
- > aims to manage their condition and its treatment in partnership with healthcare professionals
- > communicates effectively with professionals and is willing to share responsibility for treatment
- > is realistic about how their condition affects them and their family
- > uses their skills and knowledge to lead a full life.

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Box 2. Seven element care plan.

1. 'I do the things that keep me well and I will do them for the long term.'
2. 'I get the tools I need to keep me mobile, enable me to function day-to-day and manage my own health.'
3. 'I have the regular check-ups I need to stay well and get treatment quickly when I need it.'
4. 'I'm on the medications that best suit me, I know how to use them properly and I'm reviewed regularly.'
5. 'I make best use of the resources around me and my carers are supported to help me' and 'I feel supported in my caring role and get support to have a life outside of caring.'
6. 'I feel happy and able to cope with my circumstances and I know where to get help when I need it.'
7. 'I know what to do when things change, and the people that know me and my circumstances are there to support me.'

moved on from the language of self-management support to talking quite simply about the ability to 'have a good conversation', with a recognition that what is important to the patient may not be what is important to the doctor. This is particularly well captured in north-west Surrey's seven element care plan, where effective ongoing assessment, care coordination and care planning will make use of a shared support plan with essential care elements across seven core service lines (Box 2).

Understanding the challenges

Will a new partnership between patients and physicians lead to more conflicts and disagreements? Does this raise challenges and are these new?

Patients and doctors disagreeing about the right way forward, and what the best course of action is, isn't something that's new. NHS Choices makes it clear that 'NHS health professionals are trained to involve you in making important decisions. They can give you expert information and advice, and may recommend one treatment over another. But only you know what's most important to you.'³ It is this last point that is so important to patients and carers – it acknowledges the different trade-offs that different patients will be willing to make. For example, potentially delaying surgery so they can be there for their son's wedding or feeling that they simply cannot tolerate the adverse effects of a proposed new treatment even if that treatment is likely to be effective.

The potential for patients and physicians having different priorities may not be new but does shared decision making and partnership working create a different context or change expectations? Will there be scope for more disagreements?

On the part of patients, we have not seen to date, and we are unlikely to see, a sudden step change in behaviour. This is evolution not revolution and a marathon rather than a sprint. Some older people have found it more difficult to question the decision of a doctor, just as they have struggled to question the decision of any 'professional'. They are very much of the 'doctor knows best' generation. But this relationship has inevitably changed as new generations of patients and carers have

learned to question and have not seen themselves as passive participants. One of the main ways they have done this has been through becoming better informed and it is better information that has set a new framework for the conversation between patients and physicians.

While the role of patients is still evolving, the degree of change for some physicians should not be underestimated. The founding principles of the NHS were designed to 'remove the burden of care' from patient shoulders rather than enabling them to care for themselves. Disagreements and tensions will be minimised if physicians can see their role as helping patients to make real choices. This is not just about providing more information but about giving each patient the right information in the right way for them and at the right time. It is about recognising what patients can and are doing to inform themselves – 'don't make me feel guilty because I've googled' (Marlene Winfield, personal communication at the RCP).

While information is essential for partnership working, it is not a panacea. Even well-informed patients can be vulnerable and effective partnership working needs to be able to respond to this. The British Standard on inclusive service provision⁴ recognises vulnerability is dynamic, can be due to the characteristics of the service, the particular circumstances of the individual service user, or a combination of the two. It explains that 'The way modern markets, service sectors and organisations work can cause or contribute to consumer vulnerability and place consumers at a disadvantage in accessing and using products and services, and in seeking redress'. It recognises permanent, fluctuating and short-term vulnerabilities (Box 3).

The challenge for partnership working, and for physicians and patients alike, is how it can take account of these vulnerabilities.

The ethical dimension

The question is whether any of these challenges are, by their nature, ethical challenges. Will this create a new set of ethical

Box 3. Understanding different types of vulnerability.

Permanent

Permanent or long-term characteristics could include, for example, people who have learning disabilities or other permanent or long-term disabilities, those on a low income, people with low literacy levels, or communities that have cultural barriers to market participation.

Fluctuating

People can be made vulnerable by transitory situations, which are not necessarily obvious at first glance. Fluctuating characteristics might include mental health issues, English as a second language, health problems, location, or lack of internet access.

Short-term

Short-term characteristics causing vulnerability could be things related to sudden changes in circumstances like loss of employment or income, bereavement, relationship breakdown, or caring responsibilities.

tensions or issues? Are there inevitably new ethical issues arising from shared decision making?

The General Medical Council (GMC) has produced guidance and standards on patient-centred decision making and it includes advice on planning and managing conversations, handling pressures on time and resources, and delegating responsibility. It also picks up on patients who do not want to discuss, or want someone else to decide. This is vital because partnership working cannot be seen as mandatory on the part of patients. For any number of reasons, not all patients will engage with the idea of shared decision making. Some may just want to be guided by the physician to the best treatment with little participation on their part. Others – and arguably most patients – will want and would benefit from having someone with them when they have these conversations. At times of extreme anxiety and stress it is all too easy not to hear what the doctor says, to forget to ask the questions you had planned, or to only partly remember the conversation.

The GMC guidance on patient-centred decision making outlines an approach to discussing risk. This is particularly significant in reflecting on whether the *Montgomery* decision makes a difference for partnership working (Box 4). Nadine Montgomery claimed medics neglected to give her proper advice, which may have led to her son Sam having a safer caesarean birth in 1999. Her damages claim had been rejected on two previous occasions by the Court of Sessions in Edinburgh. However, judges at the Supreme Court in London have now reversed this decision and upheld her major damages claim against NHS Lanarkshire.

In responding to the *Montgomery* decision, Niall Dickson, chief executive of the GMC, described the judgement as ‘very helpful’ stating ‘we are pleased that the court has endorsed the approach advocated in our guidance on consent. *Good medical practice and consent: patients and doctors making decisions together* makes it clear that doctors should provide person-centred care. They must work in partnership with their patients, listening to their views and giving them the information they want and need to make decisions.’

This sounds neither new nor radical from a patient perspective. It seems to chime perfectly with the principles of the Expert Patient Programme, how self-management support works, and the values at the heart of NHS Choices. From a patient perspective, what is the big change heralded by the *Montgomery* decision? Is it a material change or is

this rather more about the cultural change that is required? Perhaps what *Montgomery* has done is shine a spotlight on the cultural shift that lies at the heart of partnership working and with it a reminder of just how challenging it is to effectively communicate around risk.

Risk and communication

The World Health Organization⁵ defines health literacy as the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health. ‘Health Literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.’

We know that levels of functional health literacy are low in England. Health information in current circulation is written at too complex a level for 43% of working-age adults (16–65 years); this figure rises to 61% if the health information includes numeracy.⁶ This has implications not just for meaningful communication – getting the right information to the right people in the right way – but also for good risk communication.

Risks abound in modern life, and people are bombarded by messages about risk every day. The risk-factor model for the development of diseases has opened people’s lives to scrutiny by healthcare professionals. Unfortunately, most of the information available on specific risks is, at best, incomplete. For health professionals, conveying this uncertainty to a population without generating fear and mistrust is a difficult task.⁷

Physicians are not going to get this task right by working on their own. David Spiegelhalter consistently highlights how the way that risks are ‘framed’ can make a big impression on their apparent magnitude. The controversy following the November 2015 report by the National Institute for Health and Care Excellence on hormone replacement therapy provides a timely example (Box 5).⁸

This clearly is not a one-size-fits-all approach to communicating risks and that is the problem for those who identify new ethical challenges in partnership working. The *Montgomery* ruling stated ‘There is a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments’ and ‘Whether a risk is material cannot be reduced to percentages’.¹ In its information on risks, the GMC states ‘The amount of information about risk you should share with patients will depend on the patient ... focus on their individual situation and the risk to them’.⁹

Having a conversation

Focusing on the individual situation takes us back to having the ability and time to have a meaningful conversation. ‘The doctor’s advisory role involved dialogue’ and ‘The doctor’s duty is not fulfilled by bombarding the patient with technical information which she cannot reasonably be expected to grasp, let alone by routinely demanding her signature on a consent form’.¹

Box 4. The *Montgomery* decision in quotes.

‘It materially changes the law relating to consent and we, along with other health boards in the UK, will need to consider very carefully any potential implications for future service provision’
Dr Ian Wallace, NHS Lanarkshire.

‘This is almost certainly the most significant medical negligence judgement in 30 years – a momentous decision, which will affect the doctor-patient relationship throughout the UK. Doctors will have to discuss with their patients the options that exist in their treatment and advise them about the alternatives and any associated risks.’ Fred Tyler, Balfour and Manson, Mrs Montgomery’s lawyer.

Box 5. Framing risks.

- > Describing risks in terms of its effects on populations – for example, the million women taking HRT – is sensible for public health discussion but is utterly irrelevant to the individual decision a woman has to make. If discussing a treatment choice with an individual woman, it appears to be a manipulative framing of the risks.
- > Picking on a single adverse event, even one as important as cancer, is no basis for risk communication and again seems a manipulative form of communication.
- > In a complex decision, such as whether to take HRT, in which a woman's feelings about her symptoms are so important, the potential harms and benefits to the woman should be communicated in a balanced and uniform way. The form of communication should be appropriate to her level of numeracy and wish to engage with the evidence.
- > She can then make up her own mind, based on principles of shared care and informed choice. Of course, if she wants to defer to doctorial advice, that is completely fine.

HRT = hormone replacement therapy

It is ... necessary to impose legal obligations, so that even those doctors who have less skill or inclination for communication, or who are more hurried, are obliged to pause and engage in the discussion which law requires.

What about those physicians who don't have the skills? How do you train, resource and examine doctors in their ability to do this? And for those who are not inclined to engage in these discussions, how do you motivate or persuade, monitor or ensure compliance?

Learning from other sectors

Many sectors claim to be unique but it is always legitimate to look outside and see whether there is anything to learn from other sectors. Legal services are a telling example and there are a number of legitimate comparisons.

The circumstances when you need legal or health services are similar.¹⁰ There are gaps in knowledge between user and provider; an asymmetry of information; and use of services can be infrequent. Legal services are often known as 'distress purchases' because they might cover divorce, moving house, illness and bereavement. As with healthcare, there are potentially severe consequences if bad advice is given and these circumstances are exacerbated for vulnerable consumers and create new vulnerabilities.

Some recent developments within 'unbundling' in legal services resonate significantly with the debate and challenges around partnership working in healthcare. In its simplest terms, unbundling separates a package of legal services into parts, and the client and provider agree which parts of the package they will each do. The main challenge highlighted by lawyers themselves is around assessing the client's capability. Do providers have the skills needed to accurately make this assessment? Do clients in turn have the skills and confidence? There have been questions around professional indemnity insurance, how complaints will be handled by the ombudsman, and the potential for breaching professional standards.

A court ruling in December 2015 may have provided some clarity. In *Minkin v Lesley Landsberg*, the court threw out a negligence claim brought by a client against family lawyer Lesley Landsberg. The judgment read:

It goes without saying that where a solicitor acts upon a limited retainer, the supporting client care letters, attendance notes and formal written retainers must be drafted with considerable care in order to reflect the client's specific instructions.

The judge emphasised 'An inexperienced client will expect to be warned of risks which are (or should be) apparent to the solicitor but not to the client'.

In legal services, partnership working requires clarity about the role of both the consumer and the provider with the clear expectation that the provider must still make all the risks absolutely clear to the consumer. Lawyers will need to do this and still maintain their duty to the court.

Adaptability is the future

What so much partnership working comes down to is adaptability. In every walk of life, good communication skills depend on the ability to read the signals. There is no doubt that partnership means different things in different situations and for different patients. It is not about expecting a uniform approach from physicians just as it is not about expecting all patients to behave in a set way. This is not about risking more disagreement. We are not going to see a sudden step change in informed patients but nor should the health profession underestimate the degree of change required on the part of their professional behaviour, skills and capacity.

Most patients will never know anything about *Montgomery*. If they did, they would more than likely welcome it. This could be one of those moments when, from a patient perspective you're surprised to find out something hasn't been in place long before. That only now are doctors obliged to engage in discussion, whether they have the communications skills or inclination, seems a very basic requirement.

Few patients will use the phrase person-centred care or even come across the language of shared decision making. But what more and more patients do expect is a conversation with their doctor, one in which their thoughts, concerns and, especially, their preferences are placed more equally alongside the clinician's expertise, experience and skills. This isn't about passing the responsibility to the patient or becoming a nation of health consumers. Nor is it about always meeting patient preferences at the expense of physicians exercising their duty of care. It is rather about ensuring people are given a more explicit role in decisions about their health,¹¹ achieving the informed and engaged population that is necessary to ensuring the long-term stability of the NHS.¹² ■

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