

Delivering person-centred care in long-term conditions

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ABSTRACT

The components of supporting people with long-term conditions, and the incumbent skills and resources required, are increasingly well understood. However, more coherent and systematic approaches to delivery across care pathways are required. In the setting of intermittent, discrete decisions about healthcare, the concept of shared decision making will apply. Support for self-management describes efforts to help people in living day to day with their condition(s). Care planning is relevant to proactively planning cycles of care and increasing involvement in care. The underpinning principles require a different mindset for clinicians and support for people to develop the knowledge, skills and confidence to engage and participate in their health more effectively. Achieving this could provide the holy grail of delivering high-quality care at a population level, which is consistently centred around what is important to each individual person and what they want to achieve.

KEYWORDS: Long-term conditions, person-centred care, support for self-management, shared decision making, care planning, patient involvement, patient activation, biopsychosocial

What is the problem?

Consider the challenges faced by people living with one or more long-term conditions, such as type 2 diabetes, heart failure or chronic obstructive pulmonary disease. Over years or decades living with these conditions they need to deal with the initial ‘breaking’ of bad news and accepting this into their lives; the bewildering risk of progression or complications; the relentless lifestyle and personal changes they are encouraged to make to avoid these; the complexity of multiple conditions and polypharmacy; the potential treatment decisions; as well as the psychological, emotional and social implications of each of these to the person and their families. Faced with this, is it any surprise that many struggle to incorporate this effectively into their lives and have poorer health or wellbeing outcomes as a result?

In this context, what does person-centred care in long-term conditions really mean? It certainly incorporates, but is clearly more than, ensuring dignity and respect, and a positive overall experience in clinical care settings. A much broader definition is needed to include how people experience living with their conditions day to day. Clinicians, teams and services should aim

to ensure people develop the knowledge, skills and confidence to manage their conditions effectively, navigate the obstacles they face and get the best out of the resources available to them.^{1,2}

For many clinicians, this fundamentally different relationship and approach can feel like quite an uncomfortable shift from conventional roles.^{3,4} Faced with a passive, poorly engaged patient, it is easy to see why a well-meaning clinician may revert to a traditional ‘fix-it’ mentality. However, there are a few ‘reality checks’ we need to consider to help us recognise the limitations of these approaches (Box 1).

So, having made a case that different approaches are needed, what should these actually look like? In the same way that being a chef is not just about the singular skill of ‘cooking’, it becomes evident that simply ‘being person centred’ won’t quite cover it. A complex and dynamic array of skills, tools and resources are required, underpinned by core techniques and principles, delivered with the sophistication to ensure each is available to the right person at the right time.⁵

Core principles

The core principles, or philosophy, of person-centred care epitomise making sure that each individual’s goals and priorities are at the heart of their care. However, in the context of living with long-term conditions, the person’s role as an active partner in their healthcare should also be recognised and valued.

As such, a key issue involves the sharing of power and responsibility and adopting a partnership approach, acknowledging the various assets, experiences and strengths each party brings.⁶ In the broadest sense, the clinician could be considered as the expert on the disease, with the person as the expert on their lives. Making the most of both of these will reap the greatest benefits.

A further core principle is adopting a biopsychosocial approach – taking full consideration of the biomedical aspects of the individual and their condition, but contextualising this with equal weight alongside their personal, psychological and social considerations. Holistic care – viewing the person as a whole, rather than a disease or body part – is a vital aspiration, but arguably represents a challenging counterflow to our increasingly specialised clinical pathways, particularly for people with multiple conditions.⁷

Clinicians need to demonstrate core communication skills aiming to encourage the person to tell their story, and articulate and clarify their priorities. These include the ability to express empathy and demonstrate a broad range of active listening skills, such as the use of open questions, paraphrasing and summarising.⁸

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Box 1. Whose condition is it anyway?**Reality check #1: There are very few situations where the doctor does indeed 'know best'**

Different people faced with the same clinical scenario may, for very valid reasons, have differing responses or make very diverse decisions. For instance, faced with a diagnosis of breast cancer, one woman may feel very strongly that she would like to have the breast removed, but the very next woman may feel equally strongly that this would be a catastrophic outcome for her. Both need the opportunity to talk this through, and to fully consider and understand the possible risks, benefits and outcomes of the various options, but may still end up making different decisions and living with the implications of this. Being coerced into an unwanted mastectomy may mean psychological and emotional consequences that could far offset prognostic considerations for that individual person.

Reality check #2: Most people that ask to be told what to do, don't really mean it

In a busy clinic or surgery, and faced with a patient saying 'I don't know, what do you think I should do, Doc?', it is understandable that we will frequently succumb and tell them. After all, we know what would help, and they asked, right? For some, this will be a genuine request, but before we assume this is the case, consider what happened last time they said this (and the time before that). Did they actually do what was suggested? If not, are you content to go through this cycle again (and again) or would you be better to try a different approach?

Reality check #3: Self-management is the norm

In the setting of living with long-term conditions, a person will spend just a few hours a year interacting with healthcare professionals and more than 99% of their time managing their condition themselves. We need to recognise that it is the person themselves that does most of the work and the clinician's role is to support them. People who have the knowledge, skills and confidence to manage their conditions effectively are more likely to adopt healthy behaviours and experience better outcomes.

Reality check #4: Accepting the status quo contributes to poorer outcomes

Many people do currently take a passive role, are poorly informed or feel overwhelmed by their health or life in general, which may encourage clinicians to revert to traditional roles. However, we need to recognise that these individuals are still managing their health day to day, even if they may not be in a position to do this very effectively. We should not accept or collude with this status quo, as these inequalities perpetuate poor outcomes and can be addressed by different approaches or additional support.

Practical delivery

As we consider how to put these principles into action in day-to-day clinical care, context becomes very important. Consider the various situations and challenges that a patient, Dermot, faces living with type 2 diabetes over many years and the concepts or interventions that have helped him (Box 2).

Clearly these concepts are interlinked and mutually reinforcing – each impacting on subsequent experiences. For instance, if Dermot had a poor understanding of diabetes, and

Box 2. Person-centred care in practice.

Dermot has lived with type 2 diabetes for 7 years. Shortly after diagnosis, he was referred to a structured education programme, which not only helped him understand his condition better and what could lie ahead, but also the changes he could make to prevent these problems (**support for self-management**).

At times, he has experienced feeling 'down'. He doesn't think this was due to his health or diabetes, but these did make it harder. Talking through his frustrations with his diabetes team was helpful and he also accessed peer support through the local voluntary group. Hearing that others had gone through similar things was very affirming (**emotional and psychological support**).

Dermot was aware that his diabetes control has been creeping up a little over recent years and was mindful of the potential risks associated with this. When he received his diabetes test results prior to his care planning appointment, he was disappointed to see that his HbA1c had increased a bit further. In discussion with his diabetes nurse at that appointment, he established that his goal was to try to feel better and stay healthy. Together they were able to establish that weight loss and improving his diabetes control were central to this and developed an action plan for this (**care planning**).

A few months on, Dermot was struggling to make the changes he would like, so he worked with his diabetes nurse, who supported him to think through his motivations for change, to start to make some small changes and gain some momentum (**health coaching**).

Following this, he was able to lose some weight, but the diabetes control did not improve as much as he had hoped. Following discussions with his diabetes team, and the use of a decision aid to consider his potential options, he decided that the appropriate next step was to start insulin (**shared decision making**).

He started insulin in the local group and found the education and information that he received here, along with the peer support from others in a similar position, was very powerful in motivating him to make the best use of the insulin. Over subsequent months, he gained the skills and confidence to adjust the insulin doses himself, and to make ongoing changes around weight loss, and was delighted that he achieved the improvements he was aiming for (**support for self-management**).

felt unsupported and pressured into starting insulin, it is likely he won't use it well and will fail to get the full benefit from it.

There is also a tendency for teams or services to conflate or confuse terms, or to focus on one in isolation, which may limit their effective delivery. A greater appreciation of the commonalities, but also the differences between them – their context, intended outcome and practical delivery – is needed.⁵

Shared decision making

Shared decision making is defined as a process in which clinicians and patients work together to select tests, treatments, management or support packages based on clinical evidence and the patient's informed preferences.⁹ This is relevant where a person is deciding between two or more reasonable options, such as deciding whether or not to have a joint replacement

operation, to undergo a cancer screening test or to start a new treatment (or deciding which new treatment to start).

Numerous academic publications and practical exemplars, such as the MAGIC (making good decisions in collaboration) programme, have shown that this involves supporting the person to see their role in the decision-making process, attain clear, unbiased and evidence-based information and have the opportunity to consider their options, and, where necessary, clarify their preferences and values.^{9–12} The clinician's role is to demonstrate equipoise and help the person think through the options with the outcome being that the person has made a decision that is right for them.

Decision aids and options grids are examples of written or web-based supports to achieve this and there are numerous examples available through resources such as NHS Choices, patient.co.uk and NHS Right Care. Increasingly, the National Institute for Health and Care Excellence is now incorporating patient decision aids into its guidelines, such as anticoagulation in atrial fibrillation and lipid-lowering to reduce cardiovascular risk.

A considerable evidence base has shown that shared decision making and decision aids result in people being more likely to make a decision, less likely to regret that decision and, intriguingly, they often choose the more conservative option.¹⁰ This should not be an intended outcome for this process but is relevant to a constant battle of limited resources within health services. There is also growing evidence that this may also be associated with improved health outcomes.^{9,10}

Support for self-management

By contrast, living with long-term conditions is less about specific decisions and much more about the everyday tasks and activities that a person needs to do – their self-management.² The term 'support for self-management' recognises that it is the person themselves that performs the vast majority of these tasks, and the clinician's and service's role is to support them with this. The intended outcome, therefore, is that people attain the knowledge, skills and confidence to manage their health effectively.¹³

This will involve, but is not limited to, structured education and personalised information; practical, emotional and psychological support; technologies and abilities to self-monitor their condition; and peer and community support.

The clinician's role is to support people to think through the challenges they are facing, develop their problem-solving approaches, and enable the confidence and self-efficacy to reach their goals. This reflects the adage that giving a man a fish will feed him for a day; teaching a man to fish will feed him for a lifetime.

In addition to the core skills, clinicians need the ability to offer constructive challenge, communicate risk, help people think through behaviour change and, in some cases, specific coaching approaches will be required. Avoiding being too directive and too non-committal is important, although there is a fair spectrum between these (Box 3).

Care planning

In the setting of long-term conditions and multiple care pathways, which are often focused on reacting to specific problems, there is also a need to take stock and proactively plan forwards, known as care planning.¹⁴ National Voices, a coalition of health and social care charities, describes this as

Box 3. Getting the balance right.

Faced with the following situation, which response would work best?

Clinician: So, as we have discussed, there are a couple of options for you to consider...

Patient: Oh I don't know doctor, what do you think I should do?

Response 1: I'm glad you asked. I think you should...

Response 2: Oh, I couldn't possibly say. You will just have to work it out for yourself...

Response 3: Well, I've seen a number of people in this position make different decisions depending on what's right for them. What I'd like is to try and help you make the decision you feel is right you. Tell me what ideas you've had or what thoughts you have at the moment ...

The patient's question may represent a genuine preference to be guided, but may also reflect passivity or a hesitation around their role or time to think it through. Jumping in and assuming the former (response 1) may limit the conversation and the person's involvement.

At the other extreme, this should not be confused with abandoning people to fend for themselves entirely (response 2). Exploring a little further, while normalising their uncertainty, may provide a better opportunity to work together for an outcome that is right for them (response 3).

a chance to 'plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me'.¹⁵

This is a systematic, often annual, process to ensure people have the opportunity to identify their goals, discuss options, and agree and coordinate a plan for how these goals will be met. Initially tested in the setting of diabetes, there is now considerable experience of delivering and embedding care plans as routine care, particularly in multimorbidity.¹⁶

Core to this is the sharing of results to ensure the person is 'prepared' for the conversations. Exemplar programmes, such as Year of Care Partnerships, and a recent Cochrane review, have underlined the core components of preparation, goal setting, action planning and review, along with the benefits of such an approach.^{16,17}

Implications for clinicians

This approach to person-centred care demands both a new set of skills for the clinician and a new mindset about their role. This is not rejecting the medical model, but developing or refining it for the needs of the 21st century. Imagine the impact if we applied the same meticulous and careful approaches we use to diagnose disease, to the understanding and meeting of individuals' needs.¹⁸

There is a well-documented mismatch between what clinicians believe they do and what patients actually experience, with many people wishing to take a greater role and have more information and involvement.^{2,19} Providing communication skills training without addressing the clinician's mindset, and moving from a biomedical and paternalistic approach, is likely to have limited impact.²⁰ Why train clinicians in techniques to elicit patient ideas, if they simply aren't interested in the answer? Skills training should also include reflection and development for individual clinicians, and needs support from training programmes and professional bodies.

We also need to consider other resources, systems and drivers that may encourage new ways of working and enable people to take a greater role in their care.

Overcoming passivity

It may feel overly optimistic, perhaps even naive, to espouse partnership working and a fully engaged patient role in the current setting. Certainly, genuine power imbalances do exist, that reinforce passivity and deference to the clinical role, but these are, in a large part, of our own making, perpetuated by a lack of knowledge, confidence or opportunity.²¹ These are barriers that can be overcome.

Each of the practical delivery examples above reinforces the benefit of ensuring the person is adequately 'prepared'. For instance, use of decision aids in shared decision making, and sending people their results before the care planning appointment, can change the dynamic and signal an invitation for a different conversation. These also have the potential to 'decompress' the consultation, enabling the person to think through their questions, options, preferences and obstacles prior to the meeting and, therefore, make much better use of that precious consultation time.

Other efforts to realise the untapped potential of the person, their families and communities include provision of tailored information and support, and peer support, online communities and independent information searching – essentially all the ways we access information and support outside of the healthcare setting.^{2,4,22}

Pathway design

These various components and implications need to be built into the design and delivery of effective care pathways, which are all too often focused on biomedical care. Pathways should be scrutinised to consider where decisions are made and what support is provided for this; what the person will be doing to manage their condition and how they attain the knowledge, skills and confidence to do this effectively; and how people access the resources, information and services they need.

It would be hard to imagine a care pathway where decisions (including whether or not to participate in the pathway) or support for self-management shouldn't feature. However, care planning may be more likely to occur in primary care, where the overview of multiple conditions and care pathways takes place. In the specialist setting the focus may be more about appreciating and supporting the priorities and plans that have been agreed, rather than replicating, or undermining, them.

Clinicians, services and organisations need to avoid the temptation towards a narrow focus or a 'one-size-fits-all' approach. As an example, Dermot's coaching would probably have been less successful if he hadn't already had a good understanding of his condition and understood the value of making changes.

Summary

There is an urgent need to recognise that person-centred care for people with long-term conditions necessitates different relationships and approaches to those in acute, episodic care. Central to this is the appreciation of the primacy of the person's role in their care, and the skills, resources and mindset shifts required to support this. The challenge to deliver a

comprehensive and coordinated range of interventions for populations, that is also tailored for each individual, is complex but vital. There is extensive evidence and experience from academic and exemplar programmes that have shown the way, and the benefits of effective delivery. ■

References

- 1 The King's Fund. *From vision to action: Making patient-centred care a reality*. London: The King's Fund, 2012.
- 2 Eaton S, Roberts S, Turner B. Delivering person centred care in long term conditions. *BMJ* 2015;350:h181.
- 3 Blakeman T, Macdonald W, Bower P, Gately C, Chew-Graham C. A qualitative study of GPs' attitudes to self-management of chronic disease. *Br J Gen Pract* 2006;56:407–14.
- 4 Coulter A. *Engaging patients in healthcare*. Maidenhead: Open University Press, 2011.
- 5 Lhussier M, Eaton S, Forster N *et al*. Care planning for long-term conditions - a concept mapping. *Health Expect* 2015;18:605–24.
- 6 NESTA. *The business case for people powered health*. London: NESTA, 2013.
- 7 Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition—multimorbidity. *JAMA* 2012;307:2493–4.
- 8 Stewart M, Brown JB, Weston W *et al*. *Patient-centred medicine transforming the clinical method*. Thousand Oaks: Sage Publications, 1995.
- 9 Coulter A, Collins A. Making shared decision making a reality. London: The Health Foundation, 2011.
- 10 Stacey D, Legare F, Col NF *et al*. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2014;1:CD001431.
- 11 The Health Foundation. MAGIC: Shared decision making. Available at www.health.org.uk/programmes/magic-shared-decision-making [Accessed 29 March 2016].
- 12 Stiggelbout AM, Weijden TVD, Wit MPTD *et al*. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012;307:e256.
- 13 Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff* 2013;32:207–14.
- 14 Coulter A, Roberts S, Dixon A. *Delivering better services for people with long-term conditions*. London: Kings Fund, 2013.
- 15 National Voices. Principles of care and support planning. London: National Voices, 2013. www.nationalvoices.org.uk/pages/care-and-support-planning.
- 16 Year of Care Partnerships. Available at www.yearofcare.co.uk [Accessed 29 March 2016].
- 17 Coulter A, Entwistle V, Eccles A *et al*. Personalised care planning for adults with chronic or long-term conditions. *Cochrane Database Syst Rev* 2015;3:CD010523.
- 18 Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients preferences matter. *BMJ* 2012;345:e6572.
- 19 Healthcare Commission. *Managing diabetes: Improving services for people with diabetes*. London: Healthcare Commission, 2007.
- 20 Kennedy A, Rogers A, Chew-Graham C *et al*. Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. *Implement Sci* 2014;9:129.
- 21 Joseph-Williams N, Edwards A, Elwyn G. Power imbalance prevents shared decision making. *BMJ* 2014;348:g3178.
- 22 The Health Foundation. *Helping people help themselves*. London: The Health Foundation, 2011.

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