

# The role of information and choice in patient-centred care in diabetes: a hierarchy of patient-centredness

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## Background

Some time ago, *European Diabetes Nursing* published our work questioning the concept of patient empowerment in diabetes.<sup>1</sup> There, we proposed that the difficulties with the empowerment approach stemmed from the lack of a clear, coherent, practicable definition of the term, and whether patients and health care professionals (HCPs) were willing and/or able to follow the empowerment agenda. Our work with diabetes HCPs show-cased some of the difficulties HCPs faced in getting to grips with the concept of empowerment,<sup>2</sup> and the barriers and opportunities they encountered when trying to do so.<sup>3</sup> We suggested that a return to basics was necessary and argued that the first step in achieving empowerment was to develop a better understanding of patient-centred care (PCC).

On reviewing the literature, we suggested that the way forward in diabetes was to talk about PCC rather than empowerment<sup>4</sup> on the basis

## Summary

This paper reviews some popular models of patient-centred care and acknowledges work that has questioned the measurement and effectiveness of patient-centredness in practice. In an attempt to enhance testing the concept practically, we propose a practical hierarchy of patient-centredness that we hope will aid the practical application of patient-centred care in clinical practice. The proposed hierarchy is illustrated through a practical example and the various stages inherent in it are described.

This paper concludes with a call that this theory-driven hierarchy of patient-centredness be tested out in practice with the view of confirming or revising it where appropriate so that it might serve as a useful clinical tool in future.

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## Key words

patient-centred care; diabetes self-management; shared decision making

that PCC models offer some common ground and discuss a way of practising it that is well-defined and which may result in some positive health outcomes.<sup>5</sup> Although popular and topical,<sup>6</sup> what PCC approaches have not yet done clearly, however, is to consider the concepts of information and choice, in practice. Thus, while some elements of PCC – such as patient participation, the patient-HCP relationship and the context where PCC is delivered – have recently been advocated as important in defining PCC,<sup>7</sup> it has also been argued that more stringent studies and more clarity are needed to establish in practice what aspects of PCC are important.<sup>8</sup>

Here we review the two original models of patient-centredness and consider the role of information and choice in delivering PCC. While we accept the broad principles of these models, we suggest that the concepts of information delivery and patient choice should be more specifically acknowledged to help HCPs practise PCC in a clinical context. While we have chosen to use the term 'patient-centred'

throughout this paper, we acknowledge that patients are people and the term 'person-centred' may be used synonymously in this context.

## What is patient-centred care and how is it measured?

The Institute of Medicine<sup>9</sup> defines PCC as: 'Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.' Thus, PCC is a mode of health care delivery that puts the patient at the forefront of all decision making and treatment. PCC has been associated with tangible benefits in physical and psychological outcomes<sup>5</sup> and is adopted by health systems such as the UK's National Health Service.

There are several instruments<sup>10</sup> measuring PCC, each one emphasising different aspects; however, there is not one, widely accepted, definitive model of patient-centredness. Mead and Bower<sup>11</sup> and Stewart *et al.*<sup>12</sup> have been instrumental in putting forward empirically derived models of patient-centred

tredness that may be combined into a framework of what PCC is and how it might be broadly conceptualised.

Mead and Bower<sup>11</sup> see PCC as consisting of five dimensions: a biopsychological perspective; seeing the patient as a person; sharing power and responsibility; considering the therapeutic alliance; and viewing the doctor as a person. Stewart *et al.*<sup>12</sup> on the other hand, identify six broad dimensions: exploring both the disease and illness; understanding the whole person; finding common ground; incorporating prevention and health promotion; enhancing the doctor–patient relationship; and being realistic.

Examining these frameworks together,<sup>10</sup> and focusing on their similarities rather than their differences, PCC may be conceived as a concept consisting of four components as follows.

### 1. Exploring disease and its context.

This involves the clinician considering both the presenting disease and the way the patient experiences it. In other words, a patient-centred consultation explores the physical symptoms of the illness but also the effect of the illness on the person's life and individual circumstances. This first component is presented as biopsychosocial perspective in Mead and Bower's<sup>11</sup> model and as exploring the disease and the illness experience in Stewart *et al.*<sup>12</sup>

### 2. The patient as a whole person.

Here the clinician focuses on the person as a whole, seeking to understand their illness within their biopsychosocial circumstances. This component can be understood as Stewart *et al.*'s<sup>12</sup> whole person factor and Mead and Bower's<sup>11</sup> patient as person component.

A simple example demonstrating these two factors in practice would be

to consider the effects of a diagnosis of type 2 diabetes on: (i) a middle-class professional with a heavy workload and early signs of depression; and (ii) a working-class, depression-free carer with an equally heavy workload. The two people's different psychosocial contexts in which they are asked to manage their diabetes will require a different conversation. So, the first two components are about viewing the illness and its physical characteristics in the context of, and from the point of view of, the individual patient. These two PCC components, we feel, sit within a wider health care setting. That is, they provide enough detail to help HCPs shape their consultations so that these can be patient-centred overall. These components of PCC are, we feel, an integral part of good practice and the foundations of PCC. Diabetes is a lifestyle managed illness, and, as such, it is not unreasonable to assume that clinicians with expertise in this area are well versed in this type of holistic, context-dependent care. It is for this reason that we have chosen to focus our attention on the latter parts of PCC models.

The final two components of PCC models relate to the doctor–patient relationship, and are particularly interesting with regard to the information patients are given in order to make well-informed health choices.

### 3. Doctor–patient relationship ethos.

This component is about an understanding of the therapeutic alliance. This is about HCPs showing compassion and empathy and developing a long-term relationship that is going to be conducive to decision making. This factor underlines and is related to the final component of patient-centredness that Mead and Bower<sup>11</sup> and Stewart *et al.*<sup>12</sup> have in common – namely, that of HCP and patient reaching 'common ground' or sharing power and responsibility.

### 4. Doctor–patient relationship: common ground/sharing responsibility.

This last component of PCC relates to patients and HCPs sharing responsibility in the way each conceptualises the patient's illness experience. Mead and Bower<sup>11</sup> describe the roles that the two health care partners ought to take as one of 'mutual participation'. However, as we have done previously,<sup>4,13</sup> these authors question whether in practice it can ever be possible for doctors and patients to truly share power and responsibility. Recent commentary on this issue<sup>14</sup> has also questioned whether patients are willing and able to adopt a more active role in power-sharing.

Stewart *et al.*<sup>12</sup> in contrast, explicitly talk about finding 'common ground'. They describe this as a process in which HCP and patients reach a 'mutual understanding and mutual agreement' in three important areas: problem definition; establishing the goals/priorities of treatment; and identifying the roles to be assumed by the two partners. The aim is to achieve a common understanding of the illness and, where there is disagreement or divergence, to reach a consensus.

It is this last factor, that we are particularly interested in. HCPs are primarily responsible for suggesting the available options of treatment to patients and we wonder how they may be supported in being truly patient-centred. In this context, does being patient-centred mean giving patients enough information so they can make the medically 'correct' decision or the decision that is best for them from a psychosocial perspective, especially where the latter may be at odds with the former? How can an HCP be patient-centred where what the patients think they want and need in order to manage an illness, is at odds with the medically-appropriate, health system-constrained choices that

doctors can make available to them? What happens where the two fail to find Stewart *et al.*'s<sup>12</sup> 'common ground'? Is it sensible and patient-centred to give patients the illusion of choice where the only choice is to do what the doctor recommends, or face ill health?

### The role of information and choice in reaching common ground

It is these questions that have formed the basis for our practical hierarchy of patient-centredness. The models outlined so far are very helpful in describing the overall framework within which PCC may be practised. What we feel is missing, however, is a practical guide, specifically aimed to support HCPs in approaching the information and choice they give patients within their patient-centred consultation.

In taking our understanding of PCC forward, we propose that the amount and type of information that the HCP makes available to the patient, and the giving of choice (or not) over how to manage an illness, can be more or less patient-centred *in itself*. That is, an HCP may give information about e.g. several diabetes self-management options, but not discuss implementation of this information or give enough or appropriate information about each option. Rather, the information or support given may be influenced by the HCP's personal beliefs about what option the patient 'ought to' choose. Or, it could be that both information and tools to support informed choice are given to patients, clearly and comprehensively, but the patients are not supported in making the informed choice themselves. It could be that only information pertaining to the medically appropriate 'choice' is given, which would be akin to giving no real choice. Clearly, not all information is the same and choice can be interpreted in a variety of ways.

### A proposed hierarchy of patient-centred care

For a consultation to be patient-centred, we propose that HCPs need to both give patients information and choice about how to handle information and make a treatment choice, and also support them in implementing this information with an ultimate aim of being in control of their own care. To this end, our proposed hierarchy of information and choice in PCC suggests that there are several levels of patient-centredness, with a consultation being more patient-centred the higher up the levels it rests.

#### First three levels

**Level 1: Information.** We propose that some information relevant to the patient's health will be provided; we envisage a consultation where the HCP presents patients with a range of, primarily didactic, input regarding their condition. This, we argue, would be what one would expect to see in most routine consultations, regardless of whether they were patient-centred or not. This is evidence-based information provision at its most basic level. In terms of diabetes, this would be akin to an HCP describing diabetes, its risks/outcomes and introducing aspects of self-management.

#### Level 2: Information plus choice.

We propose that information will be provided to patients as in Level 1, along with the idea that there is potentially choice between different treatment alternatives. Where treatment alternatives are not an option, we propose that, in a patient-centred consultation, the idea of choice between treatment and non-treatment is explored. In a diabetes consultation, we would suggest that the various self-management alternatives would be presented and explored, along with the possibility (and consequences) of consciously

choosing to not manage the illness. This level differs from Level 1 in that patients are introduced to the idea of having choice over how and whether they manage their illness, while Level 1 assumes that patients will want to follow an HCP's advice and follow a medical routine, regardless. So, Level 2 brings into the discussion the idea that patients may choose e.g. not to increase their physical activity or to carry on with an unhealthy diet or, indeed, fail to take tablets or insulin as recommended. Note that it is *not* proposed that patients should be encouraged to disregard HCP advice, but rather that the HCP will actively acknowledge that the patient has a choice between looking after their diabetes in the recommended manner or not.

#### Level 3: Information, choice plus tools for informed choice.

We propose that, here, patients are supported in making an informed choice themselves. Tools such as decision aids may be used here, but are not seen as essential. We perceive the concept of informed choice as that of *fully informed choice*. That is, all treatment alternatives are considered from a medical but also from a psychosocial perspective and patients are supported in arriving at fully informed choices. In the diabetes clinic, this would involve a discussion about where, when and how the person can accommodate diabetes and its management in their own social context. Using decision-aid tools such as e.g. cardiovascular risk calculators,<sup>15</sup> different self-management options can be explored with the effects of each choice clearly presented and discussed. Thus, patients are given the tools to evaluate the options presented to them and any decisions made are the result of patient-centred, *supported choice*. Building on Level 2, rather than the clinician simply

PCC level	Information	Choice	Example of typical conversation
1	Didactic and impersonal information about dietary, physical activity, blood glucose testing and medication-taking; the sort that might be available in a leaflet	No choice presented – patients must take control of their diabetes or ill health will be experienced. Patients' stories may feature in the background but are not central	<i>'You have type 2 diabetes. Diabetes is about... To control this serious illness you need to do the following... We will check on you in 6 months' time'</i>
2	As in (1) but dietary, physical activity, blood glucose testing and medication-taking information options are outlined, and generic pros and cons of tackling each are discussed	Choice between self-caring for/ignoring diabetes is noted. Patients' stories feature in the periphery in shaping the options made available to patients	<i>'You have type 2 diabetes. The illness requires a lot of changes to be made to your lifestyle. If you do X, Y, Z, the likely outcomes are A, B, C... If you choose not to do X, Y, Z, the likely outcomes are A, B, C... There are several options available and the choice is yours as to how much or little you do'</i>
3	As in (2) but each self-care option is put into the patient's context. Self-care information and options are outlined. Pros and cons of dealing with each within the patient's psychosocial context, are discussed	The outcomes of potential choices are explored fully from the patient's perspective. What may be of interest to and achievable by 1 patient may be completely different from what another patient with the same biochemical/physiological profile might choose	<i>'You have type 2 diabetes. The illness requires a lot of changes to be made to your lifestyle. Some are easier than others. But ultimately it is up to you to decide whether to engage with these and, if so, which ones to follow through and which ones to ignore. Would it help to work out what options might be viable in your circumstances? There is evidence to guide our thinking about the various options which I can tell you about once we check that these are viable options for your personal circumstances'</i>
4	As in (3) above but patient is supported to make the ultimate, informed decision for themselves	The patient outlines a self-care plan they wish to try out, on the basis of discussion carried out in (3) OR they choose to invite the health care professional's viewpoint on what action is best to take	<i>'You have type 2 diabetes. You know of all the different options available and we have discussed what would work/not work in your circumstances. We have looked at the consequences of doing nothing. Taking it all into consideration, how have you decided to take things forward?'</i>

**Table 1.** Information and choice patient-centred care (PCC) hierarchy example across the 4 levels

acknowledging that the patient has the right not to self-care as per HCP recommendations, at Level 3 the consultation expands on the idea of patient choice by helping them explore the various alternatives alongside the pros and cons of each. For example, a patient may be presented with various options about reducing their five-year cardiovascular risk. These options may include giving up smoking, making changes to their diet or increasing their physical activity. We envisage that an HCP operating at Level 3 will

present the patient with these choices and actively discuss the pros and cons of each. So, a Level 3 PCC will differ from a Level 2 PCC in that, rather than presenting patients with the idea that they may choose to self-care or not and choose from a list of self-care options, at Level 3 the various self-care options are supplemented with evidence as to their likely outcomes, likely effort needed to achieve them, likely support patients are likely to get from the health care system in achieving them and so on. So Level 3 PCC is

very much contextualised, tailored, person-centred care.

#### *Final level*

**Level 4: Patient is in full control of their care.** Here, information, choice and the tools to make an informed choice are given to patients with the ultimate aim of the patients themselves making the final treatment decision that is appropriate to their psychosocial and contextual circumstances. This informed, patient-initiated choice may well be at odds with the most 'appropriate' medical

option. Assuming the process has been followed through and a truly informed decision-making process has taken place, we argue that it is in line with adopting a patient-centred consultation to be faced with patient decisions that are judged as appropriate for the patient, but seemingly at odds with medical opinion. At the same time, and where patients have been fully informed of the various treatment options available to them, we envisage patients as being in full control of their care even in the situation where they invite their HCP to make the treatment decision for them. We propose that as long as this patient request has resulted from a process of an informed, patient-centred process, the patient can be in full control of their care by consciously acknowledging that they wish their HCP to decide on the best treatment option on their behalf. So, this fourth level of PCC can be either paternalistic or not, as long as the PCC process has been followed through the first three stages. We suggest that as long as the patient's 'voice' is the one controlling the process of the consultation, any decision that is made at this stage and as a result of Levels 1–3 having been followed, is a truly patient-centred one. Level 4, then, is about helping patients select the best self-care plan for their particular circumstances. Note that in some cases, what patients see as best for them might be at odds with what the HCP might perceive as best for the patient.

Table 1 outlines the various stages with examples to indicate the level of information, choice and typical conversation that might occur in each stage of the hierarchy.

#### What is the point of the proposed hierarchy of patient-centred care?

We have argued in this paper that, in order to be truly patient-centred, the role of information and choice

and the way that these can be handled within the context and constraints of a consultation need to be clearly determined. What we have proposed here is a theoretically-derived hierarchy which builds on existing writing but draws out what we feel is the central issue which turns good practice in to patient-centred practice. What this paper is adding to the general processes inherent in PCC, and the broad suggestions about the nature of PCC, is *the detail* on how information and choice might be handled and practised in day-to-day clinical work.

As it stands, this is a tool for reflection about clinical practice rather than about formal documentation; we anticipate that HCPs will use the hierarchy as a self-assessment tool in their consultations with the aim of noting the level of PCC they are currently practising at and the one they aspire to develop towards, within each consultation.

PCC may well appear a fluid, loosely defined concept in the absence of a tool to target specific components of the process and, here, we hope we have given clinicians a tool that can help them monitor the way they use information and choice in their PCC consultations. It is hoped that the hierarchy will be tested out in practice – and, if necessary, revised – before being adopted more widely. It is also envisaged that, following any revisions or modifications and empirical testing, a clinical tool to assess the extent to which consultations follow the hierarchy will be developed in the near future.

Recent systematic reviews on the subject seem to be supportive of the view that more stringent, clearly defined studies are needed.<sup>5,8</sup> Here, we have outlined specific, qualitatively different ways of presenting patients with information and choice in practising PCC, and we hope that clinicians will choose to test it out in day-to-day practice.

#### Declaration of interests

There are no conflicts of interest declared.

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