Empowerment in the self-management of diabetes: are we ready to test assumptions?

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Summary

This paper describes the origins and definitions of the concept of diabetes empowerment. It summarises why 'compliance' was considered to be a problematic term in diabetes and why it was replaced by 'self-management' which, in turn, paved the way for introducing the concept of empowerment. Although empowerment is a popular and helpful concept and process, it comes with several important underlying assumptions about the health care professional (HCP)–patient encounter, patient understanding, memory and willingness to become empowered, and finally the HCP's view on the validity of the concept. All these assumptions, it is argued, need further testing before the concept and process are fully and wholly embraced in diabetes care across Europe.

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Key words

Empowerment; diabetes; self-management; self-care; compliance

Introduction

Diabetes self-management continues to receive a lot of attention,[1–4] both from researchers wishing to study ways of enhancing it and from clinicians who deal with the practical aspects of their patients' self-care efforts each day. At present in the UK there is a big move towards embracing the concept of diabetes empowerment.[1–4] This paper summarises the origins of the concepts of self-management and empowerment, and critically discusses the assumptions underpinning empowered diabetes self-care. Although it is a useful term, empowerment – like compliance – comes with a set of assumptions that need to be tested in practice before it can be wholly embraced.

Compliance versus self-management

The term 'self-management' was proposed as a good replacement of the dated concept of 'diabetic compliance'[5] to describe the lifestyle and medication-taking patterns that people with diabetes engage in, in order to control diabetes and reduce the risk of complications. The very good reasons why self-management is a better descriptor than compliance have been discussed eloquently and extensively in the literature.[6–8] To summarise, it is argued that diabetes self-care is not a unitary concept but rather consists of several unrelated behaviours (e.g. remembering to take medication, reducing saturated fat intake, increasing physical activity, checking one's feet and so on). Success with performing any one of these behaviours (e.g. remembering to take medication) is well known to be unrelated to success with performing another (e.g. following a healthy diet).[9] As a result, a patient may be compliant with one area of the diabetes regimen but not another. Additionally, the complexity of the behaviours that patients with diabetes are asked to perform makes them difficult to define, let alone measure in any meaningful, standardised and objective way.[9,10] For example, while patients may be told to increase physical activity they may not be routinely given precise instructions as to how much, what sort, when, where or how to perform this behaviour. Without such details – or indeed any objective means of assessing whether they have increased physical activity – the assessment of compliance with medical advice in this case is simply not possible. This makes the discussion of compliance in diabetes nonsensical.

At the same time, it has been argued that the day-to-day choices affecting health and well-being are made by patients with diabetes, therefore they are in control at all times.[7,11] Health care professionals (HCPs) may advise, suggest and

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counsel but patients have the ultimate say over the lifestyle choices they make with respect to diabetes care. They can choose to follow advice that they have been given at clinic, or they can decide to modify it or ignore it altogether. Either way, it is rightly argued that the consequences of (and responsibility for) the choices that patients make about their diabetes accrue with the patients themselves. The HCP cannot share in the consequences of living with a demanding chronic illness, nor can they take on any of the several diabetes complications associated with poor diabetes control. Throughout, it is the patient who SELF-cares. It is therefore rightly argued that the term 'compliance' is redundant in diabetes; instead, 'self-management' better captures the complexities and realities of patients caring for their diabetes.

Empowerment and its assumptions

The emphasis of diabetes self-management is thus, clearly, on the self. Patients are in control of their illness and as such, responsible for it.

The concept of empowerment was introduced in the early 1990s, taking this idea one step further. Empowerment was defined as 'a process whereby patients have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives'.[12] It was further proposed that the concept 'is based on three fundamental aspects of chronic illness, choice, control and consequences'.[13] Finally, it was argued that empowered people with diabetes should be in a position to have sufficient knowledge in order to make rational decisions about how they manage their illness, as well as sufficient control and resources to implement their decisions, followed by sufficient experience to evaluate such decisions.[12]

This view is in stark contrast with a traditional medical model advocating expert-led care, which sees HCPs as having ultimate control over diabetes management. Unlike this model, which purports HCPs as leading brief consultations, dictating treatment plans and goals and viewing non-compliance with their advice as the patient being 'difficult', the empowerment model argues that it is futile for HCPs to attempt to take on responsibility for patients' successes or failures in diabetes self-care activities.[8] Patients are in control; the HCP simply helps patients to acquire the knowledge and skills necessary to make well-informed choices about diabetes self-management.[8,12,13]

It stems from this line of argument that where HCPs have helped patients to discover their innate ability to manage their diabetes, responsibility for these patients' health outcomes lies fully and wholly with the patients themselves. 'Professionals need to give up feeling responsible for their patients…'.[13]

Tempting though it is to embrace the concept of empowerment as the panacea of diabetes self-care and strip HCPs of the burden of worrying about patients' behaviours that are outside the HCP's control, it is argued that empowerment – both as a concept and as a process – comes with underlying suppositions that require further examination. Looking at the original empowerment definition carefully, one sees that it makes several important assumptions.

Firstly, the definition talks about empowerment being 'A process whereby patients have the knowledge, skills…'.[12] Inherent is the assumption that HCPs have communicated information about diabetes care in such a way that patients/recipients of the information receive it successfully, understand it well and remember it. The result of the consultation should be that patients and HCPs will both have a sound knowledge base, and will therefore be equal partners when making decisions about diabetes self-care. Consequently, at the end of an empowering diabetes consultation, both HCPs and patients should share the same view about the goals that have been agreed: after all, they will have both played an equal part in setting them. However, recent work[14] showed that this outcome may be quite tricky to achieve. When patients and HCPs were asked about the key issues discussed in diabetes consultations immediately after the consultation, both groups failed to agree on the diabetes-related issues that had been covered around 20% of the time. Importantly, patients and HCPs disagreed on the general self-care goals that had been decided upon, just under 50% of the time. This work suggests that far from perfect, patient-HCP communication which is at the very centre of empowered self-care may not always be as empowering as the definition of Funnell *et al* would call for.[12,13] It is thus argued that before we assume that patients are empowered, we need concrete evidence that our communication skills have been truly empowering. If they are not, we need to engage in systematic attempts to improve them so that issues and goals discussed at consultation are clear to patients and HCPs alike.

Secondly, the original definition of empowerment assumes that, once communicated, knowledge relating to self-care will be understood and remembered by patients.

But diabetes is associated with accelerated cognitive decline;[15] functions like mental flexibility and the ability to remember logical sequences in the short term are impaired in older people with the illness.[16] Consequently, unless patients understand and remember what has been discussed, their road to empowerment may be compromised. Recent work exemplifying the importance of this shows that in recorded diabetes consultations, patients remembered a mean of only 0.6 of the average 2.2 decisions made in each session, immediately after the consultation.[17] It is even more worrying that when researchers scanned these recordings and compared the decisions made on tape with those recorded by HCPs and patients, they found that both patients and HCPs recalled an average of 1 or 2 decisions that were never actually made on tape![17] These findings suggest that if we wish to empower, we need to check that both patient and HCP understanding and memory for agreed diabetes self-care activities are accurate. For example, HCPs and patients may benefit from jointly writing down what has been, reviewed, discussed and agreed. Any misunderstandings can then be clarified before the patient leaves the consultation.

A third assumption surrounding the concept and process of empowerment is that the patient is able and willing to take on responsibility for their diabetes and be an equal partner in the decision making that surrounds the management of their illness. This may be the case for younger patients. However, such a proposition might not be realistic for older, possibly cognitively impaired, patients with diabetes. Older adults and those from lower socio-economic and education levels prefer a paternalistic, doctor-led consultation to one that encourages mutual participation.[18] A recent review of patient-HCP communication further confirmed this, concluding that ‘it can be harmful to provide detailed information to those who do not want it and to impose choice on those who want their doctors to decide…’.[19] More research is needed to examine whether older patients with diabetes are ready and happy to turn their backs on life-long experiences of a health system where ‘doctor knows best’ and embrace a new empowered state of affairs.

Similarly, to the extent that patients are also consumers of medical advice, it has been suggested that some people can make decisions jointly with HCPs, but might be reluctant to do so for other reasons. As Lupton says, ‘When the highly paid specialist said the decision to have a fancy medical test was up to me, I knew “empowerment” had gone too far. I was paying him to make the decisions. But he was acting like the junior partner in my health care. I might have yelled “Power to the People” in some demo 20 years ago… but I didn’t actually mean power to me over every technical decision that would crop up in my life… I long for the old doctor-as-God, for the expert that would tell me what to do rather than lay out the odds.’[20]

Although joint decision-making may be at the heart of an empowering consultation, not all patients may be willing to take on an active role in decisions surrounding their diabetes. It might plausibly be argued that choosing to abdicate responsibility to a HCP is in itself an empowerment exercise, but a systematic review argues that ‘Unless individuals are willing to take on the responsibility that empowerment allows them the whole concept would be ineffectual’.[22] Either way, for empowerment to work in practice HCPs need concrete evidence as to where their diabetes patients stand, with regard to having the motivation and willingness to be equal partners in a consultation and in the subsequent management of their illness. Until we adopt measures aimed at assessing patients’ preferences for information and decision making, as well as their motivation and confidence in their own ability to self-manage in routine diabetes care, ultimately we will never know whether patients have truly signed up to an empowered state of affairs.

Cultural variations may also mediate the extent to which this assumption can be met across different medical regimes and older adults in Europe. Depending on how strong and entrenched the medical model is in different countries, patient resistance to empowerment in the traditional sense may vary throughout the region.

Finally, the empowerment concept assumes that HCPs are able, willing and consciously in favour of dropping the traditional medical model in which they have been trained for the opportunity to work as equal partners with patients. As yet, no research shows that, among others, diabetes consultants believe that patients are their equals; or that they believe that a consultation ascribing to the empowerment ideals is the way forward for good diabetes control; or that they have the skills, aptitude and resources to move into empowering consultations. As with patients, there are bound to be different degrees of resistance to the concept, especially in European cultures where the medical model is still in force. Empowerment may well be good for patients’ health, but unless HCPs firmly decide that it is also good for their health, its implementation across culturally diverse European set-ups is likely to be compromised.

Conclusions

So, are self-management and empowerment useful constructs in diabetes? Absolutely. Anderson and Funnell's[8] arguments as to why compliance is an ill-thought concept which has no place in diabetes are perfectly plausible and laudable. It is true that patients are ultimately responsible for their diabetes self-care: they live with the consequences of their decisions and, as Glasgow and Anderson argue,[11] HCPs cannot share in this. However, if we propose that diabetes self-care is placed wholly into patients' hands, we must ensure that they truly are empowered before we abdicate responsibility for their care. Before jumping on the empowerment bandwagon, we need to collect evidence to ensure that we are continuously meeting the assumptions with which the concept comes. We need evidence that HCPs' communication skills are indeed empowering; if they are not, we need to enhance them. We need to be sure that patient knowledge and understanding of diabetes management and the consequences of poor glycaemic control meet some minimum, widely acceptable standard. We need to have assessed patients' and HCPs' memories for self-care recommendations and be satisfied that is sound and that patients have the tools and motivation to make rational decisions about their illness. Recent work arguing that '… a consensus should be reached to agree a standardised measure and definition of empowerment'[22] may also help towards a better understanding and utilisation of the concept of empowerment in diabetes care.

Empowerment in diabetes care is certainly a sensible and practical way forward. But the transition from a traditional paternalistic model of care needs to be made carefully. Until we identify ways of satisfactorily testing the empowerment assumptions discussed above, and we have data to show that they are met in clinical practice, we should approach the concept and process of empowerment cautiously. Otherwise, we risk replacing a concept such as compliance – which we have rejected on the basis of inappropriate assumptions – with a new one that carries a different set of assumptions which we fail to meet.

Conflict of interest statement:

None

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