

'First do no harm': the potential shortfalls of empowerment in diabetes

KG Asimakopoulou, P Newton, S Scambler

Following on from our previous work¹ on the subject of empowerment and the debate that resulted,² in this paper we plan to highlight four areas of potential conflict between the concept of empowerment as it is currently defined and practiced, and the edict that we 'first do no harm'.

Initially, empowerment was defined as a process to help patients take responsibility for their own care.³ Our first concern is that the definition has moved on over the years and has metamorphosed into something rather different. It is reasonable to suppose that the concept would change over time but it is now proposed that empowerment is about "*providing patients with what they want and need*".^{2,4}

Clearly, while some patients might want and need responsibility for their own care, not all will be able, or willing, to take on such responsibility – a problem with the empowerment concept that we identified previously.¹

Authors

KG Asimakopoulou, BSc, PhD, CPsychol, CSci, Senior Lecturer in Health Psychology P Newton, BA, MSc, Research Associate S Scambler, BA, MSc, PhD, Lecturer in Medical Sociology

Correspondence to:

King's College London, Dental Institute, Oral Health Services Research and Dental Public Health, Denmark Hill, Caldecot Road, London, SE5 9RW, UK e-mail: koula.asimakopoulou@kcl.ac.uk

Received: 11 December 2009 Accepted: 27 January 2010

Abstract

This paper builds on our previous work on empowerment that has identified areas that are problematic for the practical application of the concept of empowerment in the real world, and in particular in clinical settings. What this paper seeks to do is to provide an informed theoretical critique of the practical application of empowerment in an attempt to take the concept, and the debate surrounding it, forward. In doing so, we hope to lay the foundations for assisting healthcare professionals (HCPs) to apply the concept appropriately and constructively in clinical practice through highlighting some of the actual and potential ramifications of the empowerment approach.

Key words

Self-management, empowerment

A further serious problem, which arises with this latter definition of diabetes empowerment, is that what patients want and need might clash with the principle that underpins all healthcare interactions, and which proposes that a healthcare professional's (HCPs) primary responsibility has to be to 'first do no harm'.

Anderson and Funnell seem to be proposing that, following a gauging of the patient's understanding and provision of tailored health-related advice and information, patients should be encouraged to guide HCPs according to what they think is the best course of action in the management of their diabetes. The assumption is that patients' decisions would automatically be appropriate and beneficial for health.

This holds true even when their decisions may be contrary to, and/or insufficient in terms of current clinical advice, or create an inappropriate course of action (for example, the choosing not to act).⁴ Clearly, this suggestion does not sit comfortably alongside a 'first do no harm' principle, and we argue that it is problematic and needs further clarification.

More clarity regarding the

specifics of empowerment and what it does and does not assume is also needed. If the empowerment process helps people to take control of their diabetes, this needs to be clearly stated. If it is about giving patients what they want (which in some cases might involve passing on responsibility for their diabetes to a HCP, as per the traditional paternalistic, adherence-driven models) then this also needs to be stated.

A definition of empowerment which proposes that empowerment will be different things to different people (as has recently been suggested)⁴ is neither helpful nor practicable and could be potentially damaging to the patient's health. Giving people access to any health resource through any educational philosophy is likely to improve their health. What the empowerment approach brings to enhance this potential for improvement needs to be distilled, not expanded, to catch the benefits of a range of approaches. We propose that a brief, clear, up-to-date definition of empowerment is adopted by those seeking to practise empowerment. The principles underlying diabetes



empowerment recently proposed by Anderson and Funnell go some way in doing this.⁴

The second problem that we have previously identified with the empowerment approach is the inherent assumption underlying the theory that HCPs will be able and willing to disregard years of professional socialisation into an acute care/compliance paradigm, and sign up to empowerment.

We accept that a theory or concept cannot possibly apply to all HCPs; a good theory however, based on scientific principles rather than assertions, needs to be testable, clearly defined and create a position from where replicable predictions can be made. We are not suggesting that empowerment should, or indeed does, fit with all HCP's consultation styles; to do so would be as absurd as the suggestion that good communication skills on the part of the HCP are not an underlying printhe empowerment ciple of approach. But HCPs who want to practise empowerment need to know exactly what skills they need to demonstrate, and to what degree, before it can be said that they are being truly empowering (and as such, be able to evidence their practices, and thus, the approach).

Along similar lines, an HCP who has been socialised to conduct consultations following their own agenda might wish to switch into the empowerment initiative, but might find the switch difficult and problematic. Research has looked at some issues that HCPs face when trying to adopt an empowerment approach.⁵ What this work demonstrably shows is that HCPs who are interested in adopting the empowerment paradigm will need support in doing so; we do not believe it is enough to ask HCPs to 'change' their consultations; they need to be explicitly told how to change them, and be supported, monitored and evaluated throughout the process.

We argue that at this stage it is necessary that concrete, structured, theory-driven, HCP-specific communication programmes are developed, which are aimed at supporting HCPs in their switch to empowerment. Such programmes need to be developed after consultations with HCPs who are already practising (or believe they are practising) empowerment.

We would also tentatively suggest that developing research relating to the circumstances and types of consultation, where empowering approaches can be effective and are appropriate, may required, to inform these be programmes. Such programmes, once developed, established and most importantly evaluated, need to become the gold standard for HCPs to follow; it is not enough to hope that HCPs will understand, adopt and deliver empowerment in isolation. A clear, measurable, evaluative process is needed to support HCPs in this change and to ensure and maintain quality care. In the UK, an example of such a programme is known as the Diabetes Counselling and Empowerment Course.

Although not yet formally evaluated, this course specifically addresses empowerment-aspiring HCP's communication skills: anecdotal reports suggest that participants find the work helpful. Weneed programmes such as these to be made widely accessible if, folowing formal evaluation, they are found to be successful in helping HCPs make the switch to empowerment-inspired consultations. A third problem that we previously identiwith the empowerment fied approach concerns the assertion that patients should have "sufficient knowledge to make rational decisions, sufficient control and resources to implement their decisions and sufficient experience to evaluate the effectiveness of those choices".6 We would like to focus on the first element of this proposition, namely that empowered patients should have sufficient knowledge to implement their decisions. Anderson and Funnell proposed that empowerment is not an all-ornothing process; people may be empowered to different degrees.⁴ They further propose that there is no gold standard in empowerment and the degree to which one is empowered varies between people.⁴

This concept of a continuum is interesting but it still begs the question as to what we consider as sufficient knowledge. To move from an assertion that 'sufficient knowledge' is necessary, as was argued originally, to suggest now that what is sufficient will vary from one individual to another, and is hence undefinable, is not a rationally defensible position. Surely, if empowerment is linked with having some knowledge about one's diabetes, there has to be a minimum standard of knowledge which, HCPs and patients alike, should be able to agree is 'sufficient'.

To use an analogy, if we were using the principles of empowering education in the training of pilots, we would surely want to be able to say that among the body of knowledge we would consider 'sufficient' to fly one's own plane, there would have to be elements such as knowing and being able to demonstrate how to take off, cruise and land. A suggestion that 'different pilots will reach different degrees of flight fitness' - and that therefore we cannot agree boundaries of 'sufficient' knowledge that all pilots must have is patently absurd.

A second issue here relates to what Funnell *et al*⁶ describe as a 'rational decision'. We suspect that in the current spirit of empowerment as meaning different things to different people, depending on where they are on the empowerment continuum, a definition of 'rational' is probably problematic.



But surely there needs to be some consensus on what we should be aiming to observe in patients' behaviours in order to conclude that they are making rational decisions? One could ask what constitutes a rational decision, or who decides what is rational? Is, for example, a patient's decision/ choice not to act to correct high blood glucose levels as would be their empowered right under the latest empowerment definition – rational because the patient has chosen it, or is it irrational and hence problematic, because it clashes with a 'first do no harm' approach?

It is our contention that rather than hoping that patients may engage in rational decision making, that they are actively guided towards behaviours that are based on the 'first do no harm' principle. This may well infringe empowerment in its purest sense (although, if, as seems to be proposed, empowerment is anything anybody wants it to be, such an infringement of the concept might not really be an issue).

We propose that HCPs and patients alike should be consulted and, as in the case of HCPs, a concrete, structured. diabetesspecific programme of education and psychosocial support is developed, which will act as the patient's passport to empowerment. It is true that some patients will use their passport more than others and travel further than others in their journey towards empowerment; some might become fully 'Westernised', to use Anderson and Funnell's latest analogy.⁴ But surely, HCPs would find it useful to know just how empowered patients feel, to ensure

that they provide the most appropriate support and care. In terms of content, we propose that such programmes should be developed from a 'first do no harm' principle.

Related to the above argument is a, perhaps, more fundamental issue. Having sufficient knowledge to act does not automatically entail having the capacity and resources to do so. As Bauman notes, "All of us are doomed to the life of choices, but not all of us have the means to be choosers".⁷

Finally, patients and HCPs do not function in a vacuum: they function in respective societies and in healthcare systems within diverse corners of the world. There has been very little discussion about the necessary pre-requisites for diabetes empowerment to happen in real-life health systems, despite the fact that empowerment does not and cannot happen in isolation; HCPs work within, and are constrained by, health systems which, ultimately, might be more or less supportive of empowerment-inspired ideas. Practical considerations on how to best practise empowerment within non-US systems, which may or may not facilitate the processes, have not been considered.

We propose that empowerment may work better in some systems than in others; that differing aspects of the approach may be augmented by, or be made possible, within different systems. It is necessary that we learn from observations of what does and does not work well in practice. We need to be able to distinguish the features of those health systems that are supportive of empowering practices. We also need to be able to identify features of those systems that hinder attempts to empowerment. We then need to work out ways of facilitating the latter on their way to becoming more empowerment-aligned.

To reiterate, before we conclude that empowerment is good for HCPs and good for patients, data are needed to show that this is the case. In a world of evidence-based medicine, it is ludicrous to suggest that a concept which we struggle to define, measure, assess and evaluate has to be good for people, simply because what we did before was deemed bad for them. Large randomised controlled trials, designed on the (hopefully clarified) principles surrounding empowerment are needed, before we accept that the empowerment myth firstly does no harm and, secondly, is something that we should be advocating.

References

- Asimakopoulou KG. Empowerment in diabetes: are we ready to test assumptions? European Diabetes Nursing, 2007;4:94–7.
- Funnel MM, Anderson RM. Empowerment and self-management of diabetes. *Clinical Diabetes* 2004;22:123–97.
- 3. Anderson RM. When we assume. A commentary on the assumptions underlying the empowerment approach to diabetes care and education *European Diabetes Nursing* 2007;4:98.
- Anderson RM, Funnell MM. Patient empowerment: myths and misconceptions. *Patient Education and Counseling* 2010 79;3:i277–282n press).
- 5. Adolfsson ET, Smide B, Gregeby E, *et al.* Implementing empowerment group education in diabetes. *Patient Education and Counselling* 2004 53:319–24.
- 6. Funnell MM, Anderson RM, Arnold MS, *et al.* Empowerment: an idea whose time has come in diabetes education. *Diabetes Educator* 1991 17:37–41.
- Bauman Z. Globalization: The Human Consequenes. Cambridge: Polity Press, 1998.

Conference Notice

46th Annual Meeting of the European Association for the Study of Diabetes (EASD) 20–24 September 2010, Stockholm, Sweden Contact website: www.easd.org