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Patient Empowerment: Myths and Misconceptions

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Abstract

Objective—The purpose of this article is to clarify the concept of empowerment and to correct common misconceptions about its use in diabetes care and education.

Methods—The patient empowerment approach is well suited to helping patients make self-selected changes related to weight, nutrition, and physical activity. Although the concept of patient empowerment has become an integral part of diabetes education, an accurate understanding and authentic application of empowerment has not occurred as readily. The empowerment approach is clarified and common misconceptions have been corrected.

Results—Embracing empowerment means making a paradigm shift that is often difficult because the traditional approach to care is embedded in the training and socialization of most health care professionals (HCP).

Conclusion—Unlike the traditional approach, empowerment is not something one does to patients. Rather, empowerment begins when HCPs acknowledge that patient are in control of their daily diabetes care.

Empowerment occurs when the HCPs goal is to increase the capacity of patients to think critically and make autonomous, informed decisions. Empowerment also occurs when patients are actually making autonomous, informed decisions about their diabetes self-management.

Practice Implications—Clarity about all aspects of the empowerment approach is essential if it is to be used effectively.

1. Introduction

Patient empowerment is a process designed to facilitate self-directed behavior change. With type 2 diabetes the empowerment approach is designed to help patients choose personally meaningful, realistic goals, especially goals related to weight loss, nutrition, and physical activity. The empowerment approach is particularly appropriate in type 2 diabetes because the recommended behavior changes involved deeply embedded aspects of the patient's daily life. To maximize the chance for success, patients must be internally motivated (e.g., “Losing weight is really important to me.”) rather than externally motivated (e.g. “My doctor wants me

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to lose weight.”).⁽¹⁾ However, wide spread misconceptions about the empowerment approach constrain its effectiveness. The purpose of this article is to better articulate our view of empowerment and to correct misperceptions about it in hopes of enhancing its authentic and effective use in diabetes care and education.

In the eighteen years since we presented the philosophy of patient empowerment as a viable approach to diabetes care and education,⁽²⁾ a great deal has changed.⁽³⁾ While initially controversial, it has endured and become an integral part of diabetes education practice around the globe.

While empowerment has become part of the taxonomy of diabetes education, a complete and accurate understanding of this concept has not occurred as readily. For most health care professionals (HCPs), truly embracing empowerment as an overall approach to diabetes care and education means making a significant paradigm shift.⁽⁴⁾ Making such a shift is difficult because the training and socialization of many HCPs is profoundly embedded in a traditional approach to care.⁽⁴⁾ Rather than making a genuine philosophical shift to empowerment, many HCPs attempt to incorporate empowerment into their current beliefs and practices. As a result, there are many misconceptions about empowerment and what it means to practice in ways that are consistent with this philosophy.

2. Why Empowerment?

The term empowerment was popularized by Paulo Freire. The following quote describes his view of education and provides the basis for his definition of empowerment.

There is no such thing as a neutral education process. Education either functions as an instrument which is used to facilitate the integration of generations into the logic of the present system and bring about conformity to it, or it becomes the ‘practice of freedom’, the means by which men and women deal critically with reality and discover how to participate in the transformation of their world.⁽⁵⁾

Paulo Freire's work spoke to us because we believe that his ideas accurately described the state of diabetes education as it was, and how we felt it ought to be. When we first introduced the concept of patient empowerment, most HCPs viewed diabetes patient education as a process whose underlying purpose was to increase patient “compliance or adherence” with diabetes care recommendations.^(6,7) We (and others) felt that a more appropriate and realistic purpose for diabetes patient education was to increase the learner's freedom/autonomy (i.e. one's capacity to make informed decisions) rather than increase the learner's conformity/compliance (i.e., one's willingness to follow the instructions of those in authority). This view is consistent with Freire's view of education. Thus, Paulo Freire popularized the term empowerment; we simply adopted it.

3. Empowerment: A Process and an Outcome

Freire viewed empowerment as both a process and an outcome. Empowerment is a process when the purpose of an educational intervention is to increase one's ability to think critically and act autonomously. Empowerment is an outcome when an enhanced sense of self-efficacy occurs as a result of the process. However, while empowerment is an outcome, it is not a dichotomous variable, in that one is or is not empowered. Instead, empowerment is a continuous variable, more similar to a direction than a location. When using the Diabetes Empowerment Scale (DES),⁽⁸⁾ the strength and direction of change is an indication of the intervention's effectiveness.

As an analogy, if the goal of compliance-based education is to go east, then the goal of empowerment-based education is to go west. The question becomes, how far west must one

go to be considered western? Our answer is as far west as one is willing and able to go. Thus, the process and outcome is different for each of us.

Empowerment-based interventions include both a process and an outcome component. The process component occurs when the true purpose of the intervention is to increase the patient's capacity to think critically and make autonomous, informed decisions. The outcome component occurs when there is a measurable increase in the patient's ability to make autonomous, informed decisions.

4. What's the Problem with Empowerment Today?

Since our initial paper was published in 1991,(2) we have published many conceptual and research based articles and books. We have also given numerous presentations about the empowerment approach to diabetes care and education. In a survey of U.S. Certified Diabetes Educators asking them which of 12 approaches and theories (they could choose more than one) were most helpful to them in their practices, empowerment was the most frequently selected (98.2%) approach.(9) These findings would seem to indicate that the empowerment approach is well understood and used appropriately among the majority of diabetes educators. However, our experience indicates that this is not the case. We have come to this conclusion based on the questions and comments we receive from HCPs all over the world, statements in published articles purporting to understand the empowerment approach, and comments from patients with diabetes who have completed "empowerment" based education programs.

Given the widespread dissemination of the empowerment approach and numerous reports of its adoption, why are there so many misunderstandings about patient empowerment? We believe the answer lies in the difficulty of fostering the adoption of a new paradigm.(4) In most countries HCPs are trained and socialized in an approach to care based on the treatment of acute illness. However, using the acute care approach in the treatment diabetes can cause more problems than it solves. The best evidence for the disutility of using an acute care approach in the treatment of diabetes is the extensive literature on patient noncompliance.(10·11) Virtually all of this literature is based on the view that the problem is the patient's behavior rather than the HCPs approach to care, which has been seldom considered.

During their professional education, HCPs are socialized to a set of responsibilities and expectations that define their professional identity. These responsibilities and expectations become so embedded in their professional identity they do not consciously think about them; rather they see their practices through them. Our paradigm acts as a psychological version of our eyes in that we see the world through our eyes but we cannot see our eyes.

The power of this socialization process is such that one can believe in the empowerment approach intellectually and yet behave in ways that completely contradict it, without being aware of the contradiction. In our experience, paradigm shifts are seldom caused by the accumulation of new information. Rather, they occur when HCPs have an insight (an "aha moment") into such contradictions. For example, in our training programs(12) it was not uncommon for participants to say, "I just realized that I am trying to use the empowerment approach to try and get my patient to make the decision that I thought was best for them." These insights were often surprising and disconcerting, as the HCPs truly believed they embraced the philosophy of empowerment. Once HCPs become aware of such contradictions, they can resolve them only by changing their behavior or their philosophy so that the two are consistent.

5. Fundamental Principles of Empowerment

The foundational principles of empowerment, listed in Table 1, are based on observation and logical reasoning.(13·14) In our judgment, HCPs are responsible for doing all that they can to

ensure their patients are equipped to make decisions informed by an adequate understanding of diabetes self-management and an awareness of the aspects of their personal lives that influence their self-management decisions.

The socialization of HCPs to take responsibility for their patients' care and outcomes conflicts with the existential fact that patients control and are responsible for 98% of that care. HCPs often exercise their perceived responsibility by telling patients how to manage their diabetes on a daily basis even though they lack the control to ensure that their recommendations are carried out. For many patients these recommended behavior changes are difficult and in some cases impossible to carry out. HCPs often experience frustration at their unsuccessful attempts at persuasion and they blame their patients for failing to achieve recommended outcomes, labeling them as noncompliant. Many patients also become frustrated because they are unable to carry out their HCPs recommendations and often feel blamed by their HCPs.(15-16)

Our work in empowerment is based on an approach to diabetes care consistent with the principles shown in Table 1. We advocate a patient-centered approach to diabetes care that is based on these realities. Effective diabetes self-management plans almost always require the diabetes expertise of the HCP and the equally important expertise of patients about their priorities, concerns, goals, traditions, culture, values, and resources. Given the need for two distinct kinds of expertise, collaboration is necessary to develop plans that fit both the patients' diabetes and their lives.

6. Empowerment in the Real World of Health Care

Because HCPs and patients live and work in the real world, we have established methods and models to operationalize the empowerment approach. We articulated a 5-step approach to setting behavioral goals designed to help patients identify behavioral and psychosocial problems and concerns, identify the emotions related to those problems, and establish personally meaningful goals and strategies to solve their problems.(13-14) We encourage patients to think of setting goals as “behavioral experiments.” Thinking of goals this way facilitates self-reflection, problem-solving, overcoming barriers, sustaining motivation, and attaining insights about self-management and themselves.

While we used active listening skills during this process, other non-directive communication strategies, such as Motivational Interviewing,(17) may also be used to the same end.

We incorporated many of these strategies into our group education and on-going support programs by integrating behavioral and psychosocial issues with clinical issues, addressing emotional concerns, answering clinical questions, and setting behavioral goals.(18-20)

None of these strategies is unique to empowerment. Contracting and goal setting have been used in compliance-based interventions as well. The issue is not that they are used but rather it is how they are used. The purpose of goal setting in the empowerment approach is to help patients become more autonomous and learn how to make self-selected behavior changes, rather than trying to convince them to comply with goals that have been established by HCPs.

7. Clarifying the Empowerment Approach to Care

Below we will attempt to clarify the meaning of empowerment by correcting common misconceptions based on what HCPs have said to us or that we have found in the scientific literature.

7.1. Examples of not seeing what is there

Misconception: “My patients don't want to be empowered and/or they want me to tell them what to do.”

If HCPs and their patients are happy with this approach to diabetes care, we have no interest in suggesting that they change. However, when we ask if these patients all carry out the recommendations as prescribed, the answer has never been yes. The above approach often reflects a failure to recognize the responsibility patients have for their self-management decisions. The metabolic consequences of these self-management decisions are not a function of what patients or HCPs believe about the best approach to diabetes care. Metabolic consequences are a function of the actual diabetes self-management decisions and actions of patients.

Sometimes patients ask us to tell them what to do, particularly in the early phases of their illness. When this occurs, we do as they ask because empowerment is fundamentally based on meeting patient's needs, i.e., patient-centered. They are giving us the power to make specific recommendations at that time. We also suggest to the patients that if our plan no longer works well, they need to return so we can work with them to revise the plan based on their experience of trying to carry it out. Empowerment is first and foremost about helping patients get what they need and want. Furthermore, patients usually take on more or less responsibility for decisions with different aspects of their treatment. For example, they may choose to defer medication recommendations to their HCP, but create their own exercise or meal plans. In all instances, patients are in charge of determining which decisions they wish to make themselves and which decisions they prefer be made by HCPs.

Misconception: “I want to empower my patients to improve compliance/adherence.”
“Empowerment means patient's doing everything they should.”

Empowerment is the antithesis of compliance. The purpose of empowerment-based interventions is to help patients learn to think critically and make informed decisions. There are certainly times when a patient's decisions are congruent with their HCP's recommendations. After all, patients generally want to be healthy and prevent the complications of diabetes. There also will be times when patients make informed decisions that are not compatible with the recommendations made by their HCP. Health care providers may know what is clinically best for a patient's diabetes; however, that does not mean that HCPs know what is best for that patient's life.

We have defined noncompliance simply as two people working towards different goals. Shifting away from compliance-based approaches gives us the opportunity to create collaborative partnerships with our patients where we can work toward common, patient-identified goals.

Misconception: “I am committed to empowering my patients.” “I am concerned about failing to empower my patients.”

We have defined empowerment as helping patients enhance and use their own innate ability to gain mastery over their diabetes.(2) While we can support our patients and help them learn to make independent, knowledgeable decisions, this does not mean that we can empower or disempower patients. Empowerment has nothing to do with giving or taking power. From our point of view, defining patients as empowered or not empowered is meaningless.

Misconception: “There are empowered patients, non-empowered patients, and patients who can't be empowered due to age, education, culture, etc.”

Most of our empowerment research has been among medically underserved minority patients living in the inner city.(20·21) While the resources they have available to manage their diabetes

are limited, their ability to assume responsibility and make informed decisions is not. When giving international presentations about empowerment, we have observed that concerns often attributed to culture are remarkably similar from country to country. While there certainly are cultural differences in the expression of a patient's sense of empowerment, the reality of living with diabetes is fundamentally the same.(22-23)

Misconception: "I am not sure when to use empowerment." "I only use empowerment with some patients; it is part of my 'bag of tricks.'" "I never use empowerment with newly diagnosed patients."

Empowerment is an overall approach to diabetes education (i.e., a philosophy), not a strategy. When we truly embrace this philosophy, our behavior naturally becomes consistent with that philosophy. Thus, all interactions become patient-centered, i.e., designed to assist patients to think and make independent, considered decisions. This is true for every encounter throughout the course of a patient's diabetes care and education.

A critical part of initial encounters with patients is discussing with them the importance of their role in diabetes self-management. Although some HCPs are concerned this discussion will be overwhelming for a newly diagnosed patient, it is no more overwhelming than being expected to carry out a variety of different self-management activities without this understanding. This discussion also gives HCPs the opportunity to describe their role as supporter and collaborator and thus establish a partnership with the patient from the beginning.

Misconception: "Empowerment-based education means you only focus on the patient's issues."

Many empowerment-based education programs, including those developed and tested by us, are "lecture-free" and content is presented based on the questions and concerns raised by the participants.(17-19) The role of the HCP is to serve as a facilitator and expert resource for this process. Generally, the HCP either answers questions directly or asks participants about their experiences with the concerns raised. This approach does not mean that HCPs are absolved of their educational responsibilities, nor does it mean patients are left to find critical information on their own. It is up to the HCP to ensure that patients have the knowledge and resources to make thoughtful decisions. Once the patients' questions and concerns have been addressed, the HCP discusses other issues that need to be addressed (i.e., taking insulin safely, treatment of hypoglycemia). HCPs are also responsible for raising their own concerns and helping patients understand the consequences of their decisions, while acknowledging the reality that the final choice is in the hands of the patient.

Misconception: "I use the empowerment approach because I let my patients eat what they want and adjust their own insulin doses."

There are two fundamental flaws to this assumption. First, making well thought-out decisions related to diabetes goes far beyond those related to clinical self-management. While self-management skills are an important component of our educational interventions, patients face a variety of decisions related to living with diabetes (e.g., choosing a physician, asking for family support, finding affordable diabetes care supplies). Second, the idea of "letting" is based on the illusion that the HCP actually is in charge of these decisions. In reality, adults with diabetes freely choose what and how much to eat and when to give or not give their insulin without the permission or daily supervision of their HCPs. The concepts of "letting" (and "getting") stem from traditional HCP roles where the goal is patient compliance (obedience). Even if one is a benevolent parent, the role remains a hierarchical one, rather than a collaboration between equals.

7.2. Examples of seeing what is not there

Misconception: Empowerment assumes that HCPs: a) “have communicated information about diabetes care in such a way that patients/recipients of that information receive it successfully, understand it well and will remember it.”, and/or b) “...are in favor of dropping the traditional medical model...for the opportunity to work as equal partners with patients.”(24)

We do not make the assumptions stated above. Making any assumptions about the behavior, attitudes, and proclivities of an entire group of HCPs numbering in the hundreds of thousands would be incorrect on the face of it. There is not much (if anything) one could say that would apply to all HCPs or every patient.

Misconception: “... responsibility for these patients' health outcomes lies fully and wholly with the patients themselves.”(24)

This is not an assumption that we make. Health outcomes are dependant on many factors including genetics, self-management decisions, the quality and quantity of health care patients receive, and financial and other resources, to name a few. However, we do assert that patients are responsible for the consequences of their diabetes self-management decisions. These consequences are but one factor (albeit an important one) among many factors that account for patients' health outcomes.

Misconception: Empowerment assumes “... 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.”(24)

This also is not one of our assumptions. This misunderstanding arises from the failure to distinguish between existential responsibility (being in charge) and the psychological issue of accepting responsibility (taking charge) of self-management decisions. We assert the existential fact that patients are responsible for the consequences of their self-managements decisions, regardless of whether or not they are aware of, accept, or act in accord with their responsibility. Clearly, there is substantial psychological variation in the degree to which patients understand and/or accept this existential responsibility.

Misconception: Empowerment assumes “...the HCP simply helps patients to acquire the knowledge and skills necessary to make well informed choices about diabetes self-management.”(24)

This statement is incorrect on two fronts. First, we have asserted that the role of the HCP using the empowerment approach goes well beyond “*simply helps patients to acquire the knowledge and skills.*” We believe that HCPs are responsible for helping patients achieve their goals and overcome barriers through education, appropriate care recommendations, expert advice, self-reflection, and social and self-management support. Secondly, regarding support, our view of empowerment has always included the need for ongoing psychosocial and diabetes self-management support (DSMS) following initial diabetes education. Our intervention research for the past 15 years has included a variety of follow-up strategies. More recently, our research has focused entirely on evaluating different systems for DSMS. Furthermore, we are and have been strong advocates for recognizing and meeting the needs patients have for long-term support.(23-26)

Misconception: “... empowerment assumes that once communicated, knowledge relating to self-care will be understood and remembered by patients.”(24)

This assumption is not only untrue it borders on the absurd. Patients are not equably able in hundreds of areas including memory and cognitive function. Furthermore, they do not need to be equally able in order to benefit from the empowerment approach to diabetes care. Empowerment takes patients where they are and helps them build their skills and knowledge

to increase the quality of their self-management and diabetes related quality of life. Empowerment is not about whether or not patients are equally able.

8. Discussion and Conclusion

8.1 Discussion

This article is intended to clarify some of the mistaken assumptions about empowerment. We are responsible for the denotation (the literal meaning) of our work, both written and spoken. However, the connotation (e.g., implications, subtext, unspoken assumptions) are created by and in the mind of the reader. In some instances, they reflect a misunderstanding of our approach to patient empowerment.

When we began our work in empowerment, we had no idea where it would lead. We simply believed it was the right thing at the right time. While in many ways the progress we have seen has been affirming and beneficial for people with diabetes, we understand why Kuhn(27) concluded that true paradigm shifts are likely to take a generation.

8.2 Conclusion

Whether the misconception statements above are based on HCPs beliefs or on assumptions HCPs believe we have made, they all stem from a fundamental misunderstanding of the empowerment approach to diabetes care and education. The empowerment approach does NOT involve convincing, persuading, “empowering,” or changing patients (or getting them to change). Empowerment does not involve doing something to patients.

The empowerment approach involves facilitating and supporting patients to reflect on their experience of living with diabetes. Self-reflection occurring in a relationship characterized by psychological safety, warmth, collaboration, and respect is essential for laying the foundation for self-directed positive change in behavior, emotions, and/or attitudes. Such reflection often leads to their enhanced awareness and understanding of the consequences of their self-management decisions.

8.3 Practice Implications

There are many approaches to diabetes care and education. Empowerment is but one approach, albeit an appropriate and effective one. What concerns us is that it is not unusual for HCPs to believe they are using the empowerment approach when in fact they are using a deeply flawed version of it based on one or more of the misconceptions discussed above. This can result in HCPs coming to erroneous conclusions about the empowerment approach when in fact their conclusions are based on their misconceptions about empowerment.

We suggest that HCPs who believe they are using the empowerment approach make an audio tape of one or more patient visits, listen to the tape and ask this question: Am I trying to persuade my patients to follow the diabetes care recommendations they have been given? If the answer is yes, then they are not using the empowerment approach. HCPs who are actually using the empowerment approach will answer yes to these questions: Do I help patients identify and address their primary diabetes concerns? Do I encourage them to talk about the emotional aspects of having diabetes? Do I help them identify and choose goals that are relevant and important to them? Do I respect their right to make decisions with which I disagree?

A lack of clarity about the empowerment approach serves neither HCPs nor their patients. Whereas clarity about any approach to diabetes care increases the likelihood it will be used effectively.

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Table 1
Fundamental Principles of Empowerment

1	Patients provide 98% of their own diabetes care.
2	The greatest impact on the patient's health and well-being is a result of their self-management decisions/actions during the routine conduct of their daily life.
3	Diabetes is so woven into the fabric of the patient's life that many, if not most, of the routines of daily living affect and are affected by diabetes and its self-management.
4	Because patients are in control of their daily self-management decisions, they are responsible for those decisions and the resulting consequences.
5	Patients cannot surrender the control or responsibility they have for their diabetes self-management no matter how much they wish to do so. Even if patients turn their self-management completely over to a HCP, they can change their mind about that decision at any time. Thus, they remain in control at all times.
6	Health care professionals cannot control and therefore cannot be responsible for the self-care decisions of their patients.
7	HCPs are responsible for doing all they can to ensure their patients are making informed self-management decisions, i.e., informed by an adequate understanding of diabetes self-management and an awareness of the aspects of their personal lives that influence their self-management decisions.
