From patient education for therapeutic failure to the failure of patient education

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To respond to the priority of diabetes-related health problems, it is said that “every individual should have access to a type of education that enables maximum development of his potential and capabilities” [1]. This raises some questions. Do we have the right educational handbook? Are we certain of where we are going with our educational programme? Ultimately, why do some educational programs fail?

Imagine. Here is a story…

Madame X consults a hospital-based diabetologist for a type 2 diabetes

Her physician had already mentioned the possibility of insulin therapy to her. She is worried about her weight (89kg for 1.70 m), her career and her overall independence. She currently holds a company representative position. When her physician refers to treatment failure, she understands overall failure.

– The diabetologist (having read the treating physician’s letter): You are here for your diabetes. It seems that your current therapy is not very effective, despite the two products you are taking.
– The patient: I’m doing as much as I can. I take my treatment, I check my glucose levels and when I am at home, I’m careful about what I eat.
– The diabetologist: We will have to change your treatment. Normally, insulin should do the job. We need only to find the right dosage. Also, at this point, I think we need to speak more about diabetes. I’d like you to participate in an education day here in the unit.
– The patient: Is that really necessary? I’ve already had a lot of information about diabetes!
– The diabetologist: Well, there’s information and information…You haven’t yet experienced a group environment with others that share similar difficulties with you.
– The patient: How does that actually work?
– The diabetologist: It takes place during one day in which you’ll go over important issues such as weight, medication, and also therapeutic objectives.
– The patient: Are we there just to listen?
– The diabetologist: It would be even better to participate!
– The patient: And I’ll still have to take insulin therapy?
– The diabetologist: I’m sorry but you’ll have to take insulin therapy and the earlier the better. A nurse will demonstrate the different instruments and will show you how to self-inject your insulin.
– The patient: It’s not because someone is going to show me how to do it that I won’t be afraid to inject myself!
– The diabetologist: That’s exactly the point of education! Education is the use of appropriate pedagogical techniques. If you’d like to know more, education is, according to our recommendations [2]1, to be integrated in the healing process and centred on the patient. It includes awareness, information, learning activities as well as psychosocial assistance regarding the disease and its treatment. During a personal and structured interview, we will establish an educational diagnosis to obtain details that will enable us to ascertain your needs and design a customized educational programme. You know, if your diabetes does not get better, we’ve all failed. You’ll see, it will go well…

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Some time later...

- The diabetologist: Hello Madam, How is your diabetes?
- The patient: Since the educational day, I must admit that it is no worse. I am beginning to understand certain things and insulin therapy is not the end of the world. My weight has remained stable but my glucose levels are lower.
- The diabetologist: And that was after only one information day. That wasn’t really education. We need to go further, especially regarding weight. I’d like to address you to an organisation dedicated to education – not at the hospital but in the city centre. They’ll put together a plan with you that will start with what we call an educational diagnosis.
- The patient: What else are they going to diagnose?
- The diabetologist: It’ll be within the scope of diabetes. If we want to achieve real change, we need to examine many different behavioural aspects, such as what you represent, what you do, what you’d like to do later on – your life project.
- The patient: How does that work?
- The diabetologist: You’ll meet with a nurse and a nutritionist who will help you identify all aspects of your behaviour towards food. Eating is practical: there is a kitchen and you’ll be able to talk about a balanced diet while preparing real meals. You’ll come and come back – you can’t really modify eating habits within just one session! After the educational diagnosis, a programme will be put together with you that will include a contract. This is a moral contract binding both of us: to show you the way and how to get there and you to modify your habits and to practice active prevention according to our recommendations.

At a later visit...

- The diabetologist: So, how is the educational programme going?
- The patient: To be honest with you, the educational sessions are going well but I can’t say that this is really education. My impression was that they were ticking boxes when they were putting together the contract and that I was completing a questionnaire for life insurance. (in a harder tone) Is that to cover your failure?
- The diabetologist: You’re quite hard...
- The patient: But, that’s what it felt like! Neither did I really like the contract concept. A contract implies equal partners whereas here, one knows things the other doesn’t know yet. And when I don’t manage to lose any weight, I feel like a failure given the means available and the trust you’ve put in me.
- The diabetologist: We need to rethink your programme...

Comments

This consultation questions the means and even the concept of patient education. The physician proposes here “services” according to a logical progression: a one-day education session followed by longer term activities. However, does the questioning of education need to be approached in terms of degrees (information, induction, or “true” education) and consequently of duration (one day, several days, or a longer program), or, rather, in terms of nature? If it were in terms of nature, the “problem” should not be to calculate the “correct length” (caricaturing: “please give me for…”) but rather to consider the care relationship in itself, and that from the very first consultation – really crucial. First of all by questioning the meaning of the words: what do the words “education”, “contract”, “diagnosis”, and even “patient”, “illness”, “conscience”, “trust” mean? With the risk of losing ourselves in the abysses of thought? With the risk of losing our Latin-pardon, our Greek. Of losing actually the meaning of an interpersonal relationship in a body/mind dialectic not transcended. Finally of losing oneself entirely.

In this second part, we will attempt with a different situation to integrate education more deeply

- The patient: Doctor, I’m requesting your opinion because I’ve just been diagnosed with diabetes. I’d been tired for some time. My family physician ordered a blood test and then informed me that I had diabetes and needed to consult you.
- The diabetologist: It appears to me that you are carrying some excess weight…
Failure of therapeutic education

Several months later

– The patient: That’s nothing new. But there’s nothing to be done. I’ve done many diets. They work at first and afterwards, I lose my willpower and put the weight back on.

(weighing) The diabetologist: You weigh 113 kg. (blood pressure) Oh, but you have high blood pressure: 175/110! (reading blood tests: glucose level 2.3 g/l, glycated haemoglobin 9.7%, total cholesterol 2.7 g/l, HDL cholesterol 0.37 g/l, triglycerides 2.9 g/l). This is not very good, you are presenting numerous risk factors!

– The patient: Risk factors for what?
– The diabetologist: Risk factors for a heart attack!
– The patient: Really! And what can I do?
– The diabetologist: I’d like to refer you to an educational structure to help you take the necessary measures to preserve your health.
– The patient (with a mocking smile): Because you’re going to “educate” me?
– The diabetologist: Please Madam, I’m being serious! We’re trying to help you play an active role in your health – to better manage yourself and also work with us.
– The patient (still mocking): And how does that work?
– The diabetologist: With group education sessions with others that have problems like you. We’ll see what diabetes is, how to control it, talk about a balanced diet and about foot hygiene.
– The patient: If you insist…

Several months later

– The patient: Hello Doctor, do you remember me? You referred me to your “educational” group.
– The diabetologist: I remember very well. So what did you think?
– The patient: From an ethnographical point of view, it was quite funny. We were there looking at each other like china dogs. Afterwards, the nurse and nutritionist did their bit about diabetes and balanced diet… But I didn’t feel very comfortable. The staff was very nice but do you believe that such talented people could actually manage me, with my personality and my history?
– The diabetologist: What do you mean by that?
– The patient: We’re working with pedagogical objectives. Do you think you can translate myself – the person I am –, into objectives? That’s education, the right learning so that a “good patient” will cooperate well with the staff? You can say whatever you want, but do you think you can really educate an adult? You certainly have not read Hannah Arendt, who says you can definitely not educate an adult, other than with the objective to dominate [3].
– The diabetologist: I remember well that you reacted strongly when I spoke about education. But it is my duty to present to you the existing means, to deliver information about diabetes and, if possible, more. Now, I agree with you that we need to go further.
– The patient: Excuse-me, not further, but differently. You know, I’ve read a bit, I’ve been on the internet, I’ve read refereed articles, as they say, about patient education. At the beginning, I thought it was all wordy talk, like a declaration of good intentions. And then at the end, it angered me that they’re confusing education that is really life-saving when proposing nicest chances for young people and that normalised and normative for ill adults. On that subject also, there’s a definitive article by Georges Canguilh- hern [4]: the only norm to be considered is the norm of life, the only person who can define it is the subject, and the only person that can modify it when he is ill and when he has the ability is again the ill adult himself. So, I’m asking you (still with a mocking smile) to re-establish one’s norms: are we doing education or orthopaedic re-education?
– The diabetologist: Your taking it all apart!
– The patient: Yes and No. I know very well that what you’re calling “the biomedical model” is not appropriate, because the approach is focussed on biological issues and is therefore restrictive. But to affirm that once you leave its scope we are automatically in real education is a little too easy. And I’m not able to comprehend this concept of educational diagnostic. With its different dimensions (biomedical, socio-professional, cognitive, psycho-emotional and the life project), I feel like I’m being dissected. Instead of a global approach, we are definitely reproducing the body/mind dualism. It brings to mind the Venus de Milo cut apart by Dalí! And how other than subjectively, can we consider the psycho-emotional element of a subject? This is outright contradiction with objectivity. It can’t be difficult to understand that when we’re looking at the object, no longer the subject… We’re left with creating quality of life scales! But to go where? We are trapped in a positivist system of science, moving away from patient and physician subjectivity: one is sometimes erased and the other is consequently highlighted. And I’ve had of enough of the focus on the sole patient: the patient this, the patient that… What about the diabetologist in all this? It is however only via an invested interpersonal relationship that things might change.

It is time to open the way.
Let’s look at another case…

– The diabetologist: We’re going to work together if you don’t mind. Let’s talk about the sense, or the non-sense, that you want to attribute to your diabetes and your weight. My role could be that of a “stimulator”, your’s could be to achieve or re-achieve your own nourished and enriched sense from what we are working together towards.
– The patient: You’re talking to me about meaning, do I need to see a psychiatrist?
– The diabetologist: No! Please do not mix things up! I’m not going to lie you down on a couch – I’m a diabetologist, not a psychoanalyst! However, if we only discuss glu-
cose levels and calories, we’re not going to get very far! It is only that if we are not conscious that the bread we are eating is also symbolic, not only will it be tasteless, it’ll also be untruthful! Words are also nourishing!

– The patient. Well, well, this is a real manifesto! OK, I agree to undertake a more profound approach, particularly regarding my weight. How do you see things happening?

– The diabetologist: Look, Madam, I think we can start with this…

The diabetologist puts up a chart showing the negative correlation between the prevalence of diabetes and the consumption of bread in recent years. He asks: do you think it is because we are eating more bread that there are more weight problems? A negative answer will lead to the issue of re-introducing some food types, whereas the conventional approach would be to reduce quantity of food intake, often perceived to be as deprivation. Therefore, it is necessary to bring about awareness of food transformation concepts and energetic density. Debate will follow regarding the food transformation process via oxidation, i.e. via combustion.

Combustion is a subject of metaphorical wealth that will initiate another process – that of symbolisation. That’s the key! Truth does not emanate from the explanation (by the healthcare provider); awareness does not come from knowledge, but it is just the contrary. Knowledge emerges from the emerging awareness. And truth comes on top of that, revealing the meaning. Knowledge is secondary. And taste it as an exotic fruit (in French, the words knowledge (savoir) and flavour (saveur) do share the same Latin etymology (sapere).

Epilogue

Today, medical practice preaches the achievement of objectives. We ourselves, healthcare professionals, are absorbed with the achievement of these healthcare objectives to the extent that we may be forgetting that a consultation consists firstly of dialogue. What is key in the clinical situations described above is dialogue – the therapeutic virtue of dialogue. Therefore, let us think about talk as remedy. That talk may cure is undoubtedly true! But how does it happen? How does it work – what is the mode of action for the talk that heals… or does not? To find out, we need to explore the link between words and the Greek concept of pharmakon (which means remedy and/or poison). This naturally invites us to read or re-read La pharmacie de Platon by Derrida [5].

But that’s not all! Medical dialogue is not only a conversation, not just an interpersonal relationship or a “two-bodies’ psychology” [6]; it is a dialectical process! To understand therefore how talk may cure, we need to introduce a new term, as a third instance. And to understand this term, we need to introduce the concepts of transfer, transference and gift. Not the gift as a form of transfer, but the transfer/transference as the form of gift. Transference, inherent to all relationships, is in itself that which reifies this aspect in the talk/pharmakon. Defined as something that is going from and to somewhere, transfer is this gift that becomes for the being a goal for him to reach for himself. In other words, the physician, supporting the transference process, will become the mediator, the ferryman who will enable the patient to be reconciled with himself (Become who you are!) The transfer/transference can then be seen as that which reveals the nature of the talk/pharmakon, which is indissolubly talk, gift and pharmakon. The transfer/transference is this gift which leads in the other to the beginning and end of its movement. Such a movement is driven by the other and the discourse of the other. Thinking about talk requires us ultimately to think about the ethical dimension of a consultation, as the other is seized in the experience of the encounter.

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References