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PATIENT EMANCIPATION BY HEALTH EDUCATION: AN IMPOSSIBLE GOAL?

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ABSTRACT

The development of patient education in hospitals received its first impetus in the U.S. For this reason, countries like the Netherlands where these developments tend to lag behind a bit, look to U.S. hospitals and literature for guidance on how to proceed in this matter. Although patient education in the U.S. has been steadily (and sometimes stealthily) creeping forward there are still many dilemmas and snags to be overcome. Some of these have gradually become clear, enabling patient educators in other countries to profit from American experience and using it whenever possible in their own situation.

Given this context, the differences in social, political, and organizational climate between The Netherlands and the U.S., provide unique opportunities for clarifying some of the issues that characterize the development of patient education.

In turn, such clarification may prove profitable for patient educators in the U.S. In view of the above, I propose in this paper to discuss some issues in patient education which may at first glance seem outdated, but are none the less unresolved.

What are the general goals of patient education, and what means do educators have at their disposal to reach these goals? Is the practical day-to-day state of the art as expressed by these means in accordance with, or at least not contrary to, the lofty ideals that somehow seem to lie behind our efforts at implementation?

Out of these general considerations emerges the dilemma which I will be dealing with in this article. After that I will outline a specific educational theory which might usefully be brought to bear on this dilemma: the theory of Paolo Freire. Having discussed its implications for patient education, I will draw some conclusions for the political issues involved as well as for the practical work of patient educators.

A decade ago, texts on patient education contained a variety of explanations for the necessity of stimulating developments in this direction. The importance of patient education was a relatively new idea and it had to be brought home with some force to those concerned [1].

Gradually, the idea became more widely accepted, even in medical circles. Currently, the introductions given in the growing number of handbooks on patient education seem to have decreased in size. They generally suffice by giving an overview of the obvious and well-documented reasons for patient education, and proceed to the work at hand: laying out rules for the implementation of programs. Examples of this approach abound [2,3]. The struggle to get patient education accepted as a legitimate and necessary part of hospital services has resulted in at least some acclaim in various influential policy-making circles. The publication in 1979 of an American Hospital Association (AHA) handbook listing the various arguments once again [4] testifies to this.

However, in the struggle for gaining acceptance, in medical circles in particular, we as educators may tend to overlook the effect of a basic incongruity in our own argumentations that by now seem firmly entrenched.

On the surface nothing seems to be wrong with the various argumentations, which are neatly condensed in the following statement by the AHA [4]:

> Informed, motivated and supportive participation in treatment by patients and their families can aid the recovery of the patient and enhance the quality of his health. Patient education, as an integral part of high quality care, provides an avenue to such improved participation.

Upon closer scrutiny, however, this statement appears to depart from the assumption that it is the physician who determines the treatment, and that the patient will go along with it all the more happily, if he knows the reasons that lie behind this decision. In short, it stems from a view that 'doctor knows best' in an essentially harmonious doctor-patient relationship; a medico-centered view. It is this view that fathered most of the huge bulk of compliance literature, and of course, the word 'compliance' itself. Not only does it literally mean to go along with somebody else's demands — even in quite recent literature comparisons are drawn between non-compliance and sin. [5, p. 114].

The medico-centered view continues to be influential and compliance in the literal sense is probably the most suitable argument for persuading the medical establishment of the need for patient education. Education and compliance are often linked together, as indicated by the title of a recent textbook *Effective Patient Education: A Guide to Increased Compliance* [6].

However, evidence that getting more information leads to more

compliance, is by no means unequivocal. Because different studies differ widely in method and aims, it is difficult to come to a general conclusion. Although in general the conclusion seems warranted that more information does lead to somewhat greater compliance, results indicate that this finding (not unexpectedly), varies with the kind of information and the way in which it is offered [7]. In a study by Roter [8], more information led to increased dissatisfaction with doctor-patient interaction. In patient education literature, exemplary cases are cited where patients emphatically refuse the advised treatment, no matter what informational pressures are brought to bear on them (see for example Ref. 6, pp. 186—187; Ref. 9, pp. 85—90). In a recent article, Heszen-Klemens and Lapinska did not find a relationship between characteristics of doctor-patient interaction and compliance [10]. Of even more interest is their finding that compliance did *not* have a positive effect on treatment result. Treatment result on the other hand, turned out to be influenced most by the patients engaging in spontaneous (non-doctor-instigated) health behavior. This piece of research is not the only one that points to the possibility that compliance in the ordinary, medico-centered sense, with its concomitant lack of control for patients, may not always be conducive to their health [11]. These findings certainly lend support to advocates of patient autonomy as opposed to compliance. Stimson [12] was the first to draw attention to the fact that patients may have their own very good and rational reasons for not obeying doctor's orders. These reasons have recently been elaborated upon in research by Conrad [13]. Studies like these are more in line with modern medical sociological theory, which long since stopped taking a harmonious view of doctor-patient interaction [14]. Lately, more attention instead is being paid to the aspect of negotiation in medical consultations [15].

Thus, when it comes to medical regimen, the word *compliance* which has long been under siege from advocates of patient autonomy (e.g. Ref. 9, p. 28) no longer applies and becomes *adherence* to a mutually agreed-upon course.

In this view, both parties have their own ideas about the best course to take and it is not taken for granted that information will lead the patient to ' supportive participation'. On the contrary, even the notion of 'informed consent' in itself is based on the possibility that information will not in every case lead to consent [16].

In sum, the call for patient information or education comes from two different directions: a patient-centered one in which autonomy is the key word, and a medico-centered one in which compliance still reigns. Although ideally these two arguments in favor of patient education do not have to be in conflict, for all practical purposes generally they are.

Of course, this incongruity has not passed by unnoticed. First, we find the complaint in patient-education literature that only 'lip-service' is being paid to a patient-centered outlook, which quickly tends to be forgotten in the implementation stage.

For example, Marian Adcock writes: 'Care givers say they believe a

major goal of patient education is to encourage and enable patients to becoming as self-sufficient as possible in managing their health affairs; yet they cannot seem to allow, in day-to-day work, the true reduction of patient dependency by giving patients access to information (like their medical charts) and allowing them to make decisions about their care and health education'. [17, p. 43].

Second, many advocates for a patient-centered approach have not only done research from this viewpoint, but provided lucid accounts of the problem as well. An especially clear statement of this position comes from D'Onofrio [18], who cites Paolo Freire as embodiment of how it should be, and then goes on to say:

> We find we cannot escape the struggle for control between proponents of existing institutions and those of the concept that education should give power to the people. Nowhere do the issues emerge more sharply than in the discussion of patient compliance with medical advice
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> [18, p. 272]

Bartlett and Windsor [19] agree with d'Onofrio on the importance of power-issues in patient education. They contrast 'ideal types' of the medical versus the educational model of health care. From their models it would clearly follow that the educational model is the most suited to patient emancipation. To what extent these models are indeed reflections of the existing situation in practice cannot, however, exactly be determined. In other literature the difference is for instance attributed to the different educational models that progressive and traditional health-care professionals depart from [9, p. 25].

In the Netherlands, where patient education has only recently emerged as a matter of interest, the 'emancipatory viewpoint' has from the outset played a crucial role and continues to do so. Recently some articles have been published on the subject, stating the dilemma. Bokma [20] states four different views from which patient education can depart (paternalistic, humanistic, organizational and emancipatory) and encourages us to be clear about the choice.

Dubbelboer [21] departing from this, argues that emancipatory goals are not being served by just providing information, and that the organizational barriers against an emancipatory policy are great.

WAYS OF SOLVING THE DILEMMA

Although the problem has been clearly stated like this at various times, few attempts have been made to provide feasible solutions. Whereas academic researchers who do not need to concern themselves with the practical implementation of patient education in a hospital, and can afford to state a clear position in favor of patient-centered research (and education), most educators in the field cannot.

Bartlett and Windsor look for a solution in advocating a more competi-

tive approach from educators towards the medical model and what it entails, stressing the importance of gaining power for the 'educational' approach as opposed to the medical one. Their implication is that in this way equal power for patients will also be favored. However, they are not very clear as to how to bring this about in concrete situations. Power, they note, 'can also be based on such factors as moral authority, knowledge, and interpersonal attraction'. Probably on a practical level, patient-educators in the field try to gain power in exactly this way.

Enhancing interpersonal attraction and moral authority, however, presupposes at least some cooperation with the medical authorities. It may well be that in the process of trying to gain power for their own viewpoints, educators inadvertedly lean a little too much to the other side and end up doing what they set out to oppose. Support for this assumption may be derived from the fact that some teaching manuals for health education in hospitals do not even state the problem [3,22].

Even if they do, they often go on by encouraging step-by-step approaches, clarity of goals (i.e. educator's goals), health beliefs to be changed (i.e. the patient's beliefs), and reinforcement models for behavior change. In this way, it turns out that although attention is given to patient's goals and needs in the process, the start and focus of educational activities seems mostly medically derived. Levin [23] comes to the same conclusion. Writers who are concerned about both implementation and patient-centeredness, like the Dutch authors I mentioned, have not succeeded in solving the dilemma in an unambiguous way. They either conclude with an encouragement to be clear about our goals, [20] leaving the actual choice to those concerned (the hospitals? the educators?) or with the statement that an emancipatory policy presupposes a mutual information-flow between doctor and patient, and in the same vein as Bartlett, stress the importance of the educational model [21].

Even D'Onofrio, cited above as a definite proponent for emancipation in patient education, rather lamely concludes her discussion with: 'education must foster open sharing of information, questions, doubts and concerns, so that providers and consumers of health care can learn from each other [18, p. 278].

The authors in the examples above implicitly or explicitly assume that an open information-flow in itself tends to be (or favor) emancipation. Exactly what this means, how it is to be achieved or how it works in practice, does not enter into the considerations. To clarify this issue, it seems worth while first to take a look at different categories of information.

Being told by the physician the standard medical regimen for your ailment in the assumption that you will go home and follow it, is information. Not very 'open' information, nor very effective in inducing either trust or compliance, but still information.

Being told the reason for the regimen, the room for adapting the rules to your own needs, the possible consequences of non-compliance and the possible ways to avoid those, is also information.

More open, and more adaptive to the goals and needs of physicians as well as patients. Although in theory doctors should not prefer one kind of patient above another, in practice most of them like those patients best, who follow their advice in a self-sufficient way.

Effective educational programs in hospitals provide the second kind of information, and in providing it, tend to influence the attitudes of patients in the direction of the 'supportive participation' embraced by the AHA. The effects are clear: not only enhanced (and more flexible) compliance, based on better understanding, but also better coping and less helplessness (see Ref. 24 for an excellent overview). If this is what emancipation is about, we certainly have a right to say that patient education fosters compliance *as well as* emancipation, and the dilemma vanishes.

However, it is my contention that doing so only confuses the issue, because this is not *not* what emancipation is about. I want to support this contention by taking a closer look at the work of the above-mentioned Paolo Freire, one of the worlds foremost authorities on the theory of emancipation. Having done so, I intend to show that at a practical level it is structurally impossible to seek the solution of the dilemma by taking 'the middle way' described above.

PAOLO FREIRE ON EDUCATION

Paolo Freire developed his educational work in the field of illiteracy in third world countries. In contemplating the fundamental issues involved, he developed a theory of education that is much wider in scope and refers to all educational activities that involve unequal relations of power [25].

Freire takes a radical position on these matters. In his view, educational activities in the usual sense only lead to further oppression of those already powerless due to lack of knowledge and other unfavorable circumstances. Treating people as lacking knowledge, i.e. as ignorant, and educating them with the information that we as educators seem to find necessary, is in Freire's opinion, itself a deed of oppression — albeit one dressed in the subtly deceiving cloak of paternalism. Real education must entail emancipation: liberating people to make their own decisions on their own terms. The central problem here is that people who are classified as ignorant by their educators, tend to think of themselves in this way as well. They discredit their own practical, experiential knowledge in favor of the emulation of knowledge and values of those who are more powerful. In this way, existing power relations are inextricably bound up with the existing, value-laden definitions of knowledge. They serve to domesticate people into consolidating their own oppression. These tendencies in education are not only encouraged by its goals and contents, but also by the methods used in the educational process. The educator tends to justify his own existence by defining his pupils as ignorant — and his pupils accept and confirm this definition in a dependency-fostering relationship.

Many educational handbooks on a variety of subjects abound with exam-

ples of ready-made teaching programs. According to Freire, 'everything in this ready-to-wear approach serves to obviate thinking'. In this way, he states, educators 'paradoxically use an instrument of alienation in what they consider an effort to liberate.' [25, p. 66].

For real emancipation (remember: 'emancipation' literally means 'freeing from shackles') to emerge, we need a radically different approach. The freedom to be autonomous and make your own decisions can be a threateningly heavy responsibility that people shy away from, domesticated as they are by the existing situation. They would rather recede into the maybe musty, but safe, folds of dependency. Moreover, telling people 'you have to be free' is a very paradoxical statement indeed. Mobilizing people towards autonomy means fostering a mutual relationship in which insight can be born, i.e. what Freire calls 'a dialogue'. In this dialogue, the educator cannot profess to have more knowledge than the people he teaches, nor can it simply be an exchange of ideas. It is an arduous process of mutual curiosity and inspiration. Thus, by actually entering into a dialogue in which they first and foremost give themselves, educators should encourage the emergence of autonomy in those whom they educate. They, in turn, would then face the task of confronting the 'establishment' with their own, independently derived notions of freedom and gain power in their own right.Freire's words on this matter are particularly apt when brought to bear on the relationship between educators and patients: 'someone who cannot acknowledge himself to be as mortal as everyone else still has a long way to go before he can reach the point of encounter' [25, p. 79].

With these memorable words I would like to end this brief overview of Freire's notions on education, and start to explore their meaning for the field of patient education.

APPLICATION TO PATIENT EDUCATION

We do not have to share the radical views which Freire departs from, to acknowledge the validity of his reasoning and its pertinence to our subject matter: patient education.

Hardly anyone will deny the fact that in the hospital situation, the doctors are a more powerful group than the patients. Freire's line of reasoning is in this respect applicable to patient education. But there is more. The dilemma between compliance and emancipation is, as we saw, usually resolved in favor of the former when it gets down to implementation. Freire's argument enables us to elucidate the reasons for this. Even his choice of words about the usual educational relationship is strongly reminiscent of the doctor-patient relationship:

> one of the basic elements of the relationship . . . . is *prescription*. Every prescription represents the imposition of one man's choice upon another, transforming the consciousness of the man prescribed into one that conforms with the prescriber's consciousness
>
> [25, p. 31]

Looking at our own educational activities in the hospital from Freire's viewpoint, we can indeed discern that the existing definitions of knowledge and power are being consolidated in two ways.

On the one hand, we can see that doctors and other educators almost automatically assume that it is *medical* knowledge that has to be disseminated by them to the patients, whereas the patients as a matter of course are not assumed to contribute by disseminating their own, non-medical knowledge to the other side.

The patients, on the other hand, share this view as a result of their own domesticated consciousness, derived from the prevailing definitions of knowledge and relations of power.

In this way, patients will naturally want to gain power by appropriating the knowledge of those in power, i.e. the doctors. Medical knowledge is seen as the gate to emancipation. From Freire's viewpoint however, it means blocking the patients *own* way of 'knowing things', transporting the values they themselves hold with the values of those in power.

On the side of the doctors, a well-meant paternalism, in which patient-education on doctors' terms and with doctors' values has its rightful place, is the most obvious characteristic.

Thus, the medical values become even more firmly entrenched in patients, thereby medicalizing them completely and transforming them into 'doctors', albeit lesser ones than their examples: the real doctors, who remain the guardians of the precious knowledge that is imparted to the patients in a well-meant effort to educate them.

The above line of reasoning clearly explains why patient education in practice tends to favor the 'compliance-pole' of the dilemma as opposed to the 'autonomy-pole'.

The distinction between self-management and self-care is relevant here: self-management as a learning goal in patient-education programs (e.g. not overeating or injecting your own insulin) presupposes medical or medically derived goals, and in this way is non-emancipatory.

As opposed to this, self-care education, as Levin [23] cogently puts it: 'derives its goals from the *learners* perceived needs or preferences, regardless of whether or not they conform to professional perceptions of the learner's needs. . . . Thus, both content and methods in self-care education help shift the control from the professional to the lay person.' [23, p. 208]. According to this distinction, education for self-care might be the most conducive to furthering emancipatory aims in Freire's sense of the term.

However, Levin goes on to say that for many reasons the hospital is not the suitable place to promote self-care: this should be done in the less medicalized circumstances of general health education.

Leaving aside the debatable issue of whether introducing health professionals into ever-new areas of public life has an emancipatory influence, I would like to return to the matter in hand: the hospital situation. From the foregoing we can safely conclude that the norms for 'knowledge' as a source of power in the hospital situation will always be derived from existing medi-

cal norms, either directly or by the circuitous route of the domesticated consciousness of patients. In the following section I will discuss different possibilities for solving the dilemma another way.

DISCUSSION

Is there any chance of success at all for a patient-educator in the hospital who would like to support the kind of emancipation advocated by Freire? Nowhere in the literature have I found an example of a hospital education program, experimental or other, that worked along those lines. As I remarked before, there is a noticeable gap in the literature between the more theoretical views stressing emancipation (as exemplified by Squyres' reader, Ref. 26) from which I cited many authors, and implementation or program manuals. To be sure, a certain kind of patient-centeredness does emerge now and again, particularly in handbooks for the nursing profession [9,27]. They stress the importance of setting goals and developing the teaching process in cooperation with the patient. They sometimes also acknowledge the dominance of the patient's right to do as he or she pleases, even to the point of rejecting treatment or advice altogether against professional insights [9].

Nursing professionals are open more than others to the viewpoint that doctor might not always know best. Nurses can be taught how to handle the resultant problems for themselves as well as for the patient in the delicate balance of power in hospital hierarchy. This is hopeful in itself. However, this kind of patient-centered education is humanistic rather than emancipatory in its aims, to keep to Bokma's [20] distinction. It is a far cry from what Freire means. What is conspicuously absent in the above examples, is the real dialogue in Freire's sense between the two chief protagonists: doctor and patient.

This dialogue, which is the foundation of his theory, would not simply entail two-way communication in which the doctor takes notice of what the patient says and cares for his or her needs as they are indicated. It involves much more: it would require the conviction on the part of doctors as well as patients, that what the patient knows is just as relevant for the art and science of medicine, as the contribution of medical science. This would mean a radical change of values for doctors and patients that falls little short of being revolutionary.

Is there a way for hospital educators to promote changes in this direction? Probably not. The difficulties seem gigantic if not insuperable as no doubt the reader may already have concluded. I will review the options. To begin with, an educator could try to take upon him or herself the task of working in this way with one of the main protagonists: the patient. However, it requires immense involvement, talent and effort to establish a real dialogue with patients in a way running counter to their expectations. Moreover, the swiftly changing population of hospital patients is hardly conducive to the long-term (and therefore costly) programs needed for such an undertaking. And, finally, if such a program were successful, it would prob-

ably be killed swiftly (and painfully) by medical specialists and hospital directors, when confronted with its products: patients who do not adapt to their role.

There is yet another option, which has until now received relatively little attention. Professional patient educators are in a (sometimes uncomfortable) intermediary position between doctors and patients. If patient autonomy were considered a priority, one way of supporting this would be to go by the circuitous route of educating the doctors first, rather than the patients. Of course, this route might be viewed as somewhat *too* circuitous. If we want to educate the doctors, why not do it in the institutions where they receive their education, i.e. in medical schools, instead of waiting to be confronted with the finished product of this education in which medico-centered values have been firmly entrenched?

If this has not yet been done, it is not for want of trying. By now, practically a whole generation of social scientists in medical school have been trying to do just that without much success. However, as such medical students may believe in these values by the time they enter the hospital, as soon as they start working there the change in the other direction is dramatic: the pressures for socialization into the established order are too great to be withstood. A whole body of literature by this time testifies to this (see Ref. 28 for an overview). Departing from well-established educational principles there is, however, good reason to assume that the best possibilities for change in this respect are on the spot, in the hospital. This goes for students and interns as well as for established specialists. In my experience on patient education committees, I have seen many times how skeptical medical specialists, in the course of working together with other professionals, gradually changed their attitude and became enthusiastic advocates of ideas they hitherto rejected. Although this in itself does not necessarily have emancipatory value, with luck and care it could grow in that direction. By engaging doctors in the real dialogue Freire is talking about, educators could help them to view the world from an 'ordinary' (i.e. non-medical) perspective. By seeing themselves as (potential) patients instead of as doctors, it might be possible for medical professionals to discover the road to freedom and emancipation from the medico-centered model for themselves as well as for their patients. Perhaps this option is illusory. In any case it would take considerable and painstaking effort. On the other hand, at least doctors, unlike patients, are in the hospital to stay. Moreover, because they occupy positions of power and authority, the fruits (if any) of such a program would be the seeds for a new harvest.

However, hospitals where the climate is conducive to this kind of program are rare, although their exemplary value from the point of view of innovation might be great. In any case, it appears that in all but the most exceptional cases the possibilities for hospital educators to work at emancipatory goals in Freire's sense, are very slight indeed. What conclusions do we draw from this for our work as hospital educators?

CONCLUSION

We must, unfortunately, conclude that patient education in hospitals is not the royal road to the emancipation of patients. Supporting programs that are patient-centered in a humanistic way, of the kind described earlier, is a realistic aim and as far as we can go. Although this will not bring about a radical change in values, it will certainly contribute to the happiness of the individuals involved. Educational work along these lines has been done and hopefully will continue and spread. This, however, is not emancipation and it is my contention that pretending it is, we will do more harm than good. Patient educators devoted to the cause of emancipation, might review their own hospital situation to see whether it might be possible to start an emancipatory program along Freire's lines with either doctors or patients. Probably it will turn out to be impossible. If this is the case, educators had better openly confess that this is not to be expected from their programs. This will help to clarify the issue, thereby enabling other forces to be brought to bear on the matter. Political pressure from consumer and patient groups should be directed to finding other ways of obtaining results, like patient self-help groups in which gaining more medical knowledge is not on the forehand the most desirable option, but instead forces are joined to get recognition for the patients' point of view as legitimate and important in its own right, as Levin [23] proposes.

If this point were to be stated clearly, patient educators themselves could get on with the business in hand, i.e. educating patients in the medical knowledge pertinent to their illness. Patients and society can and do benefit from ' ordinary' educational programs in many ways, as we all know. Making and executing health-education programs, particularly if they lean to the ' humanistic' side, is a legitimate and necessary endeavor. Moreover, its chances of success are enhanced if the medical staff can see health educators clearly and unequivocally as its helpers. Taking this stance is in contradiction with the somewhat fuzzy options provided in most publications dealing with the dilemma. Take for instance, D'Onofrio's statement:

> the goal of patient education cannot be to achieve unquestioning compliance with medical advice. Rather, education must foster open sharing of information, questions, doubts, and concerns so that providers and consumers of health care can learn from each other. In this way we can all increase our understanding and our options, decide together how best to resolve the problems of medical care, and pool our resources toward these ends. Through participatory education, then, we can find new power to achieve patient treatment goals. At the same time we will be joining forces to reshape our institutions, empowering them to serve more effectively our society's changing needs
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> [18, p. 278]

The practice of patient education by now tends to show that the process she describes, is not taking place. In this article I have given the reasons why this is impossible, both theoretically and practically. It is probably undesirable as well.

Taking this stand might be considered an unsatisfactory solution to the problem outlined. It is not. In fact, it is not a solution at all. It has been remarked that one difference in culture between Europe and the U.S.A. is, that Americans are more prone to look for a solution to every problem that presents itself, whereas Europeans, the world being as it is, content themselves by noting there is an insoluble problem and learning to live with it. As I have tried to show in this article, American experiences so far tend to show that emancipation as a goal should not be expected from educational programs in hospitals. In my opinion, the lesson we could draw in the Netherlands from these experiences is not that we can do better, but that we would do better not to try. Moreover, in our publications we should be clear about this and stop giving the impression that maybe it could be done. In this way we will avoid raising expectations that cannot be met in reality. Let's not kid ourselves into thinking that we can have our cake and eat it too — in that way we will just end up with mouldy crumbs.

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