

Participatory medicine

Jon Kabat-Zinn

Professor of Medicine, Executive Director, Center for Mindfulness in Medicine, Health Care, and Society, UMass Medical School & UMass Memorial Health Care, 55 Lake Avenue North, Worcester, MA 01655, USA, tel. +508 856 4057; fax +508 856 1977; E-mail: jon.kabat-zinn@umassmed.edu

A recent study of ours¹ showed that patients with moderate to severe psoriasis who were meditating, guided by meditation tapes, while they were undergoing UVB or PUVA treatments, cleared at about four times the rate of subjects who received the UVB or PUVA by itself in a small ($N = 37$) randomized clinical trial. We had observed a positive effect in an earlier and even smaller pilot² and did the more elaborate replication study to determine whether this was a real result.

But one question we now wish we had thought to ask the patients before they agreed to participate and again when the study was over is: 'On a scale of one to 10, how onerous do you find your phototherapy treatments?' For it was only after completing the study, when we knew who was in which group, and interviewed patients in the tape group, that we heard them say how much more positively they regarded their phototherapy treatments, in spite of the inconvenience (one patient described it as having a 'second job') because they felt empowered, felt they were participating in the process, and could perhaps contribute to making a difference in their outcomes. In fact, some felt their psoriasis was milder as a result of learning to bring their mind to their skin in the ways they learned from the tapes.

We began thinking about the project in the first place simply to see if we could make the experience of being in the light booth somewhat less stressful by actually guiding the person in meditative relaxation exercises while he or she was inside. There is no doubt that the overall felt experience of phototherapy from the point of view of the patient is a little unusual, if not outright alienating, in that one is naked, with eyes covered, often with a pillowcase over the head and therefore somewhat suffocated, under the heat of the lights, enclosed in a small space with the whirring of blowers.

But beyond the potential to make the experience more relaxing and engaging, we quickly saw the potential for using meditation coupled with delivery of phototherapy in the light booth as an experimental system for a rigorous scientific exploration of certain aspects of the mind/body connection and its relationship to healing. We therefore designed and carried out a randomized clinical trial, looking not just at how relaxing people found the experience, but also at whether there was an effect on the rate of skin clearing itself. We found this to be the case. This results suggest that participation on

the part of the patients through a meditative harnessing of their capacity to pay attention in an intentional and focused way has the potential to reduce the number of treatments and thus the cost, as well as the risk of skin cancer associated with UV exposure, in at least some patients.

Following the study, our subjects often spoke enthusiastically of the opportunity to become active participants in their own treatments, and so we regretted not having asked them to rate the degree of onerousness of the whole process pre- and post-intervention.

In spite of our oversight, there are common sense lines of thought and evidence suggesting that the medicine of the 21st century will be and ought to be far more *participatory* than what we have experienced so far. Indeed, in some studies, various participatory approaches have been shown to influence regression of coronary artery disease³ and survival in breast cancer⁴ and in malignant melanoma.⁵ As care-givers, we have to remind ourselves of what we of course already know, namely that all human beings, including ourselves and our patients have, to varying degrees but almost always far more than we suspect, deep and life-long inner resources for learning, growing, healing, and personal transformation. Part of our job will be to make available appropriate opportunities and effective vehicles for mobilizing those resources in our patients so that they can put them to work in the service of their own health, where *health* is seen as the health of mind, body, heart and soul, one seamless, unfragmented whole.

The methods available to us now are not particularly mysterious, and a great deal of work in the fields of behavioural medicine, mind/body medicine, and what is now coming to be called *integrative medicine* suggest that many if not most patients like to be invited to participate in their own health care if the invitation reflects a genuine partnership which truly honours the patient as a unique individual with a unique universe of felt experience, relationships, and meaning. Indeed, participatory medicine would go a long way toward making our health care system, which is far more aptly described at this point in time as a disease care system, into a true health care partnership, one which would of course include disease care but which would also re-integrate the patient as person into the caring in profound ways.

For the past 20 years, the Stress Reduction Clinic at the University of Massachusetts Medical Center (now UMass Memorial Health Care) has been serving this participatory role in our hospital, and this mindfulness-based stress reduction (MBSR) approach⁶⁻⁹ has now spread to over 240 medical centres and clinics in the US and abroad. The clinic, in the form of an 8-week outpatient course, is designed to catch people falling through the cracks of the health care system or not receiving full satisfaction in terms of their expectations for results of treatment. It challenges them to experiment with the possibility of doing something for themselves as a complement to what their physician and health care team are doing for them. The clinic is a service which requires a physician referral, and thus serves the needs of physicians to have a welcoming place right in the hospital where they can send their patients. Not only do the patients learn and hone the skills of self-regulation, awareness, and relaxation, but they also tap those aspects of being and attitude that shape one's appreciation for one's own life and the potential for its full expression across the lifespan, while facing and using any and all circumstances of the present moment, no matter how onerous or difficult, as the raw material for this particular inner work. There is a lot of uplift here, and we have found that most people we see, regardless of their disease or their particular circumstances, are happy to hear that, 'as long as you are breathing, from our point of view there is more right with you than wrong with you, no matter what is wrong, and that everything is "workable" if you are willing to do a certain kind of inner work in partnership with us.'

Nowadays, there is much debate in the lay press and even in medical journal editorials¹⁰⁻¹² of what has come to be called alternative medicine,^{13,14} complementary medicine, mind/body medicine, and now, integrative medicine. Ultimately, I think what we are really talking about is *good medicine*. The patients often seem to be way ahead of the practitioners in terms of their breadth of knowledge and interest in this domain. As are we, they are most interested in positive outcomes. But they are also interested in being treated with respect, and in trying sensible alternatives when other avenues do not bring full satisfaction. A lot of good science is necessary both on the more traditional biomedical side and the more, from the biomedical perspective, unconventional side. But a good deal of work has already been done in behavioural and mind/body medicine, and it is only common sense to afford our patients the opportunity to participate more fully in their own health care in imaginative ways. Would we want any less for our own family members or for ourselves?

References

- 1 Kabat-Zinn J, Wheeler E, Light T. *et al.* Influence of a mindfulness meditation-based stress reduction intervention on rates of skin clearing in patients with moderate to severe psoriasis undergoing phototherapy (UVB) and photochemotherapy (PUVA). *Psychosomat Med* 1998; **60**: 625-632.
- 2 Bernhard J, Kristeller J, Kabat-Zinn J. Effectiveness of relaxation and visualization techniques as an adjunct to phototherapy and photochemotherapy of psoriasis. *J Am Acad Dermatol* 1988; **19**: 572-573.
- 3 Ornish D, Brown SE, Scherwitz LW. *et al.* Can lifestyle changes reverse coronary heart disease? *Lancet* 1990; **336**: 129-133.
- 4 Spiegel D, Bloom JR, Kraemer HC, Gotthelf E. Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet* 1989; **2**: 888-891.
- 5 Fawzy FI, Fawzy NW, Hyun CS *et al.* Malignant melanoma: Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Arch Gen Psychiatry* 1993; **50**: 681-689.
- 6 Kabat-Zinn J. *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. Delacorte, New York, 1990.
- 7 Kabat-Zinn J. Meditation. In: Moyers B, *Healing and the Mind*. Doubleday, New York, 1993: pp. 115-143.
- 8 Salmon P, Santorelli S, Kabat-Zinn J. Intervention elements promoting high adherence to mindfulness-based stress reduction programs in the clinical behavioral medicine setting. In: Shumaker SA *et al.*, eds. *Handbook for Health Behavior Change*. Springer, New York, 1998: pp. 239-266.
- 9 Santorelli S. *Heal Thy Self: Lessons on Mindfulness in Medicine*. Bell Tower, New York, 1999.
- 10 Angel M, Kassirer JP. Alternative medicine - the risks of untested and unregulated remedies. *N Engl J Med* 1998; **339**: 839-841.
- 11 Jonas WB. Alternative medicine - learning from the past, examining the present, advancing to the future. *JAMA* 1998; **280**: 1616-1618.
- 12 Fontanarosa PB, Lundberg GD. Alternative medicine meets science. *JAMA* 1998; **280**: 1618-1619.
- 13 Eisenberg DM, Kessler RC, Foster C *et al.* Unconventional medicine in the United States. *N Engl J Med* 1993; **328**: 246-252.
- 14 Eisenberg DM, Davis RB, Ettner SL *et al.* Trends in Alternative Medicine Use in the United States. 1990-97. *JAMA* 1998; **280**: 1569-1575.