An Internist' Journey with Behavioural Medicine

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About the Author

Dr. William Goldberg was born in Hamilton, Ontario in 1925 and earned his MD from University of Western Ontario in 1949. He did his post-graduate residency at Victoria Hospital in London, Ontario and the Toronto General Hospital in 1954 and received the Honorary Doctor of Science at McMaster University in 1998. Dr. Goldberg was a clinical professor of medicine at McMaster and was Chief of Medicine at St. Joseph's Hospital in Hamilton from 1962-1982.

This is the story of a Behavioural Medicine Unit that was developed in 1975 at St. Joseph's Hospital in Hamilton Ontario. It explains why a general internist decided to assemble a team skilled in the principles of cognitive behavioural therapy to help patients who were responding poorly to traditional medical care. The principles that were applied at that time continue to be as important in 2015.

Despite the success of the program and of others that were developed over the next 40 years, these principles have not been adequately utilized by 'main stream' medicine nor have they been emphasized sufficiently in undergraduate or residency curricula. It is hoped that the story will stimulate the promotion and integration of the principles of cognitive behaviour into medical education and patient care.

Changing people's behaviour can be extremely challenging because it usually requires changes in the management of deeply held beliefs. It is my thesis that nearly all human behaviour results from one's beliefs and I hope to convince readers that the successful application of cognitive behavioural principles requires changes in the beliefs of both patients and their doctors.

The journey began during my residency at Victoria Hospital in London, Ontario and later at the Toronto General Hospital. I was mentored by two outstanding clinicians, Dr. Frank Brien and Dr. Ray Farquharson. Part of their greatness as clinicians was their desire and ability to understand their patients' adaptations to their illness. In main stream medicine, patients' responses to their illnesses often influenced their management; when a specific diagnosis could not be made, management was based on the patient's response to their illness. As I look back 65 years, I realize they were practising behavioural medicine. Dr. Brien often said, "The most difficult patient to treat is the one for whom there is no specific treatment". The truth of his

statement became obvious to me in the 1960s when I began seeing patients who presented with disabling symptoms but had no defined disease, or whose degree of disability was far out of proportion to that expected with their disease. These patients usually had symptoms of recurrent, atypical, chest pain or profound fatigue and investigations failed to show defined disease or disorder. I conjectured that if I could reassure them that they had no 'organic' disease and took the time to enquire about possible emotional problems, exposure to excessive stress, and ask them whether they were deeply concerned that they had a serious underlying disease, that they would improve. I naively thought that, with reassurance and realization that their symptoms were influenced by emotional factors, they would get better. Accordingly, I proceeded to counsel them in this way, but the vast majority did not improve and still believed they had some disease that had not yet been diagnosed.

To make matters worse, for those patients with chest pain, emergence of cardiac ultrasound identified mitral valve prolapse were referred to cardiologists. Most patients with chest pain underwent this test and many had mitral valve prolapse because this benign condition is very common in the general population. Affected patients were then told the mitral valve prolapse was the cause of their chest pain and thus, they were given the diagnosis of having an 'organic' disease. This label exacerbated their problem. Some became aware of palpitations from benign extrasystoles and presented to the emergency department with their chest discomfort, where they were examined and investigated and had the diagnosis of mitral valve prolapse confirmed. The response of the medical profession reinforced their belief that they were unwell and increased their illness behaviour, and, thus their level of disability.

The chronic fatigue patients whom I saw had a condition that had been known to the medical profession for over 100 years as neurasthenia. It was not until the 1990s that the disorder was given the label of chronic fatigue syndrome. This was considered by many to be caused by chronic brucellosis and later by the Epstein Barr virus. Both were later proved not to be causal agents. Even to this day, though no cause has been found, it is considered by many to be a disease with an organic cause. Labeling these patients with a disease for which there is no specific treatment worsens their situation.

A Better Approach

In the late 1960s, I thought that there must be a better approach to manage patients who were being referred to me with undiagnosed chest pain or chronic fatigue. They were being referred to me in what appeared to be epidemic numbers. I thought I might be missing an underlying psychiatric disorder so I discussed my dilemma with Dr. Norman White, then the Chief of Psychiatry. We decided to interview these patients together to see if we could devise an approach that combined psychiatric and internal medicine expertise. Soon, we noted a common thread among our patients. They were very hostile to their doctors because they thought that they were not believed and that their doctors thought they were either crazy or lying. In our interviews, we jumped on this belief system and devised a plan based on convincing our patients that we thought their symptoms were real, that they had no mental disorder, and that they were not lying to us. After using this new approach in several patients, we reviewed their progress at a follow-up visit 2 to 3 weeks later and asked each patient what they thought our message to them was. To our surprise, with minor variations, they all felt we believed that they were crazy or lying. Thus, simply telling patients what we considered to be the truth, was not enough to change their beliefs.

In 1974, the first Behavioural Medicine Unit was initiated at the University of Pennsylvania.¹ To try and incorporate the principles of cognitive behavioural methodology to our clinic, we asked Dr. Arny Cott, a psychologist in cognitive behavioural therapy, to join our interviews. He concluded that the interviewed patients demonstrated what he called the 'disease-illness distinction.' This term is best explained by considering two extreme examples of a spectrum. At one extreme is a person with no defined disease who demonstrates disabling illness behaviour and is off work on disability pay, while at the other extreme is a paraplegic who demonstrates no illness behaviour because he/she works full time, is involved in athletics, and is only limited physically by paraplegia. Dr. Cott opined that it was not the presence of an underlying

disease, but the patient's overall response to their symptoms that caused their severe illness behaviour. The term illness behaviour refers to the response to illness (real or perceived) as it affects the patient's activities of daily living. This response mechanism had been clearly outlined in a 1961 publication by Dr. David Mechanic² whose title was its message, 'Response Factors in Illness, Study of Illness Behaviour.' This message is as pertinent today as it was in 1961.

It was also noted that these patients demonstrated avoidance behaviour due to a false attribution of causality. This latter term refers to the need for a person to attribute any event in their lives, such as illness, to a specific cause. False attribution is exemplified in our patients by their belief that they had some undiagnosed disease or a minor disorder that they believed was causing symptoms; the symptoms were far out of proportion to those expected with the disorder.

In addition, Dr. Cott then conceived the hurt/harm concept, which is typified by patients' beliefs that activity would worsen their underlying condition. He felt if we could convince our patients that although an activity might hurt, it would do them no harm, that they might cooperate with a cognitive behavioural program. He also felt that if this program set incremental realistic goals that led to a slow increase in activity, with progressive success at each level, patients would alter their belief system. Thus, by demonstrating that carrying out a behaviour, which is incompatible with their belief that they have a serious underlying disease, they might change their belief. For example, he predicted that our patients with chest pain who believed they had heart disease and who were able to carry out an exercise program, would realize that this activity was incompatible with their belief that they had serious heart disease.

Our early results were promising. In 1975, we formed a multidisciplinary clinical unit at St. Joseph's Hospital called the Environmental Medicine Unit because Dr. White felt that our patients' personal environment, which included their family, their social life, and their work environment played an important role in reinforcing patients' illness behaviour. Eventually, it was renamed the Behavioural Medicine Unit. Dr. Cott was the Director and was responsible for planning and implementing a cognitive behavioural program for each patient. Dr. White and I would participate in the initial assessment process and we were available to reassess patients when medical or psychiatric problem arose.

The key to the success of the unit was its multidisciplinary nature. Dr. White and I were given the responsibility of ensuring that the patients' medical and psychiatric status had been fully investigated, and when medically necessary that

they received best available therapy. If we had doubt about our diagnosis, we would seek appropriate consultation. The main purpose of this initial phase of the program was to 'demedicalize' the component of their illness behaviour that could not be accounted for by a known disease process. This left Dr. Cott with a free rein to deal with the demedicalized portion of their illness behaviour by implementing a cognitive behavioural strategy.

Each patient's program was determined at an initial conference, chaired by Dr. Cott, where we all met and discussed our opinions. We also included staff that were our field consultants. The latter had backgrounds in psychology, nursing, or social work and underwent education and training programs in cognitive behavioural principles. They assessed the home, family and work environments as well as the social milieu, to look for factors which might be exacerbating illness behaviour. In addition, they liaised with family doctors and, when appropriate, consultants who had evaluated the patient. An important component of the field consultant's role was to ensure that patients received a single message from all involved in their care. If they received a single message from all concerned, they were much more likely to change their beliefs to coincide with those that the program was trying to instill. The planned program was implemented by the field consultant in the patient's home and, when necessary, their work place. In retrospect, it seems obvious that a plan, which included treating the patient in their home and that encouraged involvement of, and reinforcement from, the family should improve compliance and increase the likelihood of changing the patient's behaviour. The ready availability of medical and psychiatric input and its integration into the program helped to legitimize the unit in the eyes of the patient, the referring doctor, and the medical community. In the late 1980s, Drs. Cott and Anchel carried out a study³ to assess the value of field consultants. They found that 84% of field-managed patients had a successful outcome compared to 61% of those treated solely in the office. Equally important was the much higher dropout rate in office--treated patients.

Initially, we had difficulty in obtaining patient referrals because the cognitive behavioural component, which accounted for the major portion of the cost of the program, was not covered by the provincial health plan. In addition, practising doctors were not aware of cognitive behavioural methodology nor of its potential to benefit patients. Once we demonstrated success with patients in the work place who were disabled and on sick leave or long term disability, or in

litigation for accident related injuries, the clinic activity grew dramatically. The motive for the referrals from these sources was related to the favourable cost-benefit outcome if we could return patients to their work place and reduce or discontinue disability payments, but the most important benefit was the return of an unhappy disabled patient to a normal life style and gainful employment.

Beliefs Changed

In the late 1980s, a study was carried out by Jane McCully, one of our field consultants, who was working towards her PhD at McMaster University. Aware that a paper⁴ published in 1980 reinforced our experience that reassurance alone nearly always failed to alleviate disabling illness behaviour, McCully based her thesis on a study of patients with chest pain and no evidence of cardiac disease and an assessment of their response to cognitive behavioural reshaping. The patients were initially tested for their locus of control, and were all found to have an external locus of control. Namely, they believed external factors over which they had little control dictated their behaviour. In addition, they kept a pain diary before, and throughout, the treatment process of the cognitive behavioural reshaping program. The 43 patients who were in the treatment cohort all returned to a normal life style and believed they had no heart disease. All treated patients were retested for their locus of control and, after completing the program, had all changed from an external to an internal locus of control. This meant that before they entered our program, they believed they were not in control of their lives, but after completing the program, they believed that they were in control. Thus, two major beliefs that were important factors in the production of their illness behaviour were changed by the behavioural treatment program. Another significant finding was noted when we compared their pre- and post- treatment pain diaries. This finding was that 13 of the 43 treated patients had more frequent chest pain after completion of the program than before, yet they had a normal life style. They were asked how they could reconcile this paradox and their uniform answer was that they knew the pain was not caused by underlying heart disease and they otherwise felt so well that they must have just learned to live with it. This finding exemplifies the hurt/harm concept, in which the patient believes that a discomfort will do no harm even though it hurts, because of the belief that it is not caused by heart disease. The patient believes that he/she is in control and as a consequence demonstrates minimal if any illness behaviour. McCully succeeded in obtaining her

PhD and we later published a paper that outlined her results.⁵ A similar study was performed with patients diagnosed with chronic fatigue syndrome and the cognitive behaviour program demonstrated a reduction in illness behaviour and a high rate of return to work.⁶

There is now evidence from PET scanning and functional magnetic resonance imaging of the brain that supports the proposal that expectations of symptom improvement, long thought to play a critical role in the placebo effect, are driven by the prefrontal cortical areas and the ventral striatum.⁷ Placebo stimulates an increase in endogenous endorphins and dopamine production, which the authors suggested, could be the mechanism for the success of the placebo effect. I would propose that the findings associated with exposure to a placebo apply to our notion that belief drives illness behaviour. To apply those findings to our thesis, the patient must first cognitively believe in the projected expectation of improvement, which we contend, is then mediated through the brain resulting in an increase in endorphins producing less pain. This results in feeling better and so lessens illness behaviour.

Paradigm Shift Needed

Today, there is a need for a paradigm shift in clinical medicine from a purely biomedical model to a biomedical-behavioural one. The biomedical model can be defined as follows: A disease or disorder produces signs and symptoms which are the sole basis of the investigations, diagnosis and treatment.

disease->symptoms->investigation->diagnosis->therapy

The biomedical-behavioural model considers the role of the individual human behavioural response in the process of any disease or non-disease situation because this is what dictates the way in which the patient demonstrates illness behaviour. A more accurate and inclusive model is illustrated by the following: A disease or disorder produces signs and symptoms to which the patient responds resulting in some degree of illness behaviour, the extent of which must be recognized with any diagnosis and included in the diagnostic and therapeutic process.

*disease->symptoms->patient response>diagnosis
->illness behaviour-> therapy*

With this model, the degree of illness behaviour that occurs may be appropriate to the known effects of the underlying disease or may be inappropriate. This is where the disease/illness distinction comes into play. The patient's response mechanism can be as important as the direct effects of the underlying disease or disorder. Therefore the response mechanism should be given the same emphasis in clinical medicine, clinical investigation, and medical education that is lavished on defined diseases.

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