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Chronic illness and compliance

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Chronic illness and compliance
For a person with a chronic illness, life is altered in some way. Whether simple or complex, changes are nevertheless permanent. A patient with a chronic disease assesses recommended treatments on how well they can be integrated into his life. Evidence suggests that an individual's perception of his situation will determine whether or not he will comply with a medical regimen. Health professionals neglect the patient's point of view if they believe that patients regard the health professional as an absolute authority, thereby contributing to non-compliance. The contingency contract provides a model of patient–provider transaction, which requires input from both parties. The health professional can work with the person to make the medical regimen compatible with the individual's lifestyle.

INTRODUCTION

Mr Jones is a 71-year-old man admitted to hospital with a myasthenia gravis, a diagnosis of several years duration. As usual, Mr Jones is experiencing double vision, generalized weakness, shortness of breath and difficulty swallowing. Because he is afraid to swallow, Mr Jones is losing weight. Although when first diagnosed Mr Jones' disease seemed well controlled with medication, exacerbations have become more difficult to control. When admitted to hospital this time, Mr Jones' condition deteriorated rapidly until he had a respiratory arrest. However, he was successfully resuscitated. Mr Jones was then started on plasma exchange treatments, a procedure which separates plasma from blood components in a centrifuge. Protein-bound antibodies that interfere with neuromuscular function are contained in the plasma, which is discarded.

Mr Jones' physicians believe plasma exchange is the only treatment alternative left. Hopefully, Mr Jones can be maintained on phoresis treatments until his medications begin to work. After 2 weeks of treatments, Mr Jones' condition remains unchanged. He refuses his treatment despite the fact he is aware it may be his only hope. Mr Jones' physicians believe plasma exchange should be continued. Why is Mr Jones' perspective different?

REDEFINING CHRONIC ILLNESS

In fact, Mr Jones' decision may not be so unusual. Estimates of non-compliance with medical regimens range from 30 to 60% (Becker & Maiman 1980, Marston 1970, Sackett & Snow 1979). For individuals with a chronic illness, non-compliance rates generally tend to be higher. For example, over 50% of patients with hypertension or tuberculosis fail to remain under medical care (Sackett & Snow 1979). Compliance with dietary advice averages 50% or less (Ekerling & Kohrs 1984). Compliance rates in chronic illness are fixed roughly at 50% (Ekerling & Kohrs 1984, Fennerty 1978, Jette 1982, O'Brien 1980, Sackett & Snow 1979).

A consistently high incidence of non-compliance among chronic disease patients suggests there is something about chronic disease which may contribute to non-compliance. A look at the literature on specific chronic diseases provides some answers. The life of the emphysema patient, as described by Fagerhaugh (1975) is an illuminating example. Due to irreversible lung damage, oxygen intake in the emphysema patient is reduced. Exertion can cause respiratory distress, so life for the emphysema patient becomes restricted to those activities which a limited oxygen and energy supply can serve. Therefore the patient regards therapy as useful, if it can enhance mobility. Emphysema patients may overuse sprays to relieve the respiratory distress which inhibits desired activities. By contrast, inhalation therapy provides little immediate relief. Patients prescribed inhalation therapy two or three times a day may not comply because returning home for treatment uses too much energy.

Similarly, renal patients on haemodialysis find activities limited to those in proximity to a dialyzer. Dietary restrictions of protein, sodium, potassium and fluid are necessary to help maintain the physiological balance, which is disturbed by impaired renal function (Hume 1984). In fact, studies of dietary compliance among dialysis patients show significant non-compliance rates (Becker & Maiman 1975, Blackburn 1977, Hume 1984). Bone demineralization, pruritis, insomnia and sexual impotence may occur (Abram 1970). Some patients on long-term dialysis, in an extreme form of non-compliance, withdraw from dialysis programmes or refuse to follow dietary and fluid restrictions and thus commit 'passive suicide' (Abram 1970). In fact, the suicide rate among long-term dialysis patients is high (Abram *et al.* 1971).

Opiates may be prescribed to the patient with ulcerative colitis to facilitate bowel movement control. However, Rief (1973) suggests opiates may be used to the point of overdosage when such a patient attempts to meet social demands outside the home. Some ulcerative colitis patients will eat very little in order to reduce the number of bowel movements, although this is not a recommended method of bowel control (Reif 1973).

In patients with rheumatoid arthritis, pain can be so incapacitating that mobility becomes severely limited (Weiner 1975). Inflamed or deformed weight bearing joints also contribute to reduced activity. In addition, medical regimens may be complex, for example requiring ingestion of medication, as well as use of assistive devices, splints and daily exercises (Jette 1982). The time and energy that complex regimens require may not be worthwhile. As a regimen becomes more complicated, compliance declines (Becker & Maiman 1980). In an attempt to maintain normal activity, the rheumatoid arthritic patient may forego prescribed daily rest periods.

For all these people, chronic illness means a permanent deviation from the normal, caused by unalterable pathological changes. Residual disability is common. Rehabilitation may require special training for the patient and a long period of supervision, observation or care. These delimiting elements comprise a definition of chronic illness written by the Commission on Chronic Illness in 1956. However, a dimension of chronic illness, exemplified in the above illustrations, is unrecognized by this definition. Chronic illness requires a permanent alteration in the individual's way of life. For the emphysema patient whose lungs can provide only enough oxygen for limited activity, the nature of the disease necessitates a lifestyle change. Others, like some hypertensives need only adapt to a simple pill-taking regimen. For this patient it is the treatment regimen which demands a change in the way of life. Treatments may offer survival. For the end-stage renal patient dialysis means life. Other chronic disease patients follow regimens for symptom management. For example, the patient with arthritis uses aspirin to reduce persistent and chronic pain. Chest physiotherapy in cystic fibrosis is used to prevent pulmonary complications but will not effect a cure. Emphysema patients may use inhalation therapy to relieve symptoms, but it may be a time consuming regimen requiring use of a scarce commodity — energy (Fagerhaugh 1975).

THE PATIENT'S PERSPECTIVE

Despite the reason for a regimen or therapy, a cure cannot be hoped for. The regimen becomes part of the individual's daily life. No matter how efficacious the treatment or how diligent the patient, he will never be rewarded with a cure.

Perhaps for this reason the importance assigned by the patient to therapy is less than that assigned by the medical personnel. Shontz *et al.* (1960) studied the effects of chronic illness upon the expressed importance of the physical body to the individual and concluded that physical health was secondary in importance to the pursuit of personal goals. Treatments are prescribed to maintain or improve the patient's health, but as Shontz *et al.* (1960) suggest, the individual will not evaluate his regimen on whether or not it allows him to maintain a state of health. Rather, as Strauss *et al.* (1984) state, regimens 'are judged on social rather than medical bases'.

That a patient's perspective will determine his decision to comply is substantiated in the health belief model, one of the most frequently researched explanations of compliance. This framework is called the health belief model because it is based on the premise that behaviour is determined by the subjective world of the perceiver (Rosenstock 1966). Although originally used to explain preventive health behaviours, the model has been expanded to explain compliance behaviour in chronic illness (Kasl 1974, Mikahail 1981). An individual's motivation to engage in health action is based on perceived severity of a condition. To ascertain the direction of action, individuals weigh the benefits of available alternatives against the perceived costs (Janz & Becker 1984, Mikhail 1981, Rosenstock 1966).

In addition, variables which predict compliance are believed to act by modifying a person's perception of severity and the benefits of taking action (Becker & Maiman 1975). Extremes of age is an example of a demographic variable. Elderly patients, a group more likely to have chronic conditions (Strauss *et al.* 1984), are less likely to be compliant (Becker & Maiman 1975). Enabling factors, such as social influence, will effect adherence behaviour. Oakes *et al.* (1970) found family expectation was a significant factor in arthritic patients' compliance to a splint regimen. Patients who believed that family members expected compliance were more likely to comply. The complexity of a regimen identifies a structural variable. For example Hulka *et al.* (1976) found patients with congestive heart failure or diabetes committed more drug errors as the complexity of the drug regimen increased. Geertsen *et al.* (1973) provide an illustration of an interaction variable that affects compliance. Arthritic patients who described their physician as 'personal' were more likely to adhere to recommended treatments. An attitudinal variable is satisfaction with care. For instance, Bartlett *et al.* (1984) used a sample that consisted primarily of patients with a chronic illness and found medication compliance was influenced by patient satisfaction with the clinic visit.

THE HEALTH PROFESSIONAL'S PERSPECTIVE

In chronic illness, the outcome of a treatment programme depends on the patient's responsibility for maintaining his regimen (Szasz & Hollender 1956). The health belief model proposes that whether or not a patient will assume and sustain this responsibility, depends on the patient's perspective. To determine the probability of compliance, the attitudes and beliefs of the patient need to be understood. This of course necessitates his input into the patient–health professional interaction. If, however, the physician and patient assume the roles delineated in Parson's description of a proper medical transaction this may be difficult (Di Matteo & Di Nicola 1982).

The sick role, as outlined by Parsons, provides a set of expectations by which the ill person is expected to abide (Callahan *et al.* 1966). These expectations describe a range of dependent behaviours which replace customary roles (Kasl & Cobb 1966). Thus the individual is not held responsible for his incapacity, but he is also exempted from normal social duties.

The conflict between sick role behaviours which are assumed by the chronic disease patient and normal social obligations are delineated by Abram (1970) in his discussion of the psychological stress engendered by chronic dialysis. In order to survive, the dialysis patient must accept his dependency on a machine and cooperate with his programme of dialysis and diet. At the same time he must fulfil normal social obligations, such as work. Because side effects of therapy such as 'post-dialysis lethargy' may occur, this can be difficult. Sick role obligations also assume the individual will seek appropriate help and get well. As the sick role is legitimated by the physician, the patient becomes passive and dependent, investing authority in his superior knowledge and expertise. Because sick role responsibilities include getting well, it is assumed the patient will abide by the physician's instructions.

This approach, of course, infers that the individual will get well. Based on a framework that presumes disease is exclusively biological (Cox 1982), those whose course of illness prevents a cure exist outside the realm of the model's assumptions. People with a chronic illness will not be cured. They must live with their disease and its effects. The 'cure' becomes a regimen which must be lived with daily.

Health professionals judge regimens on their medical worth, but patients judge regimens on social bases (Strauss *et al.* 1984). Thus a discrepancy exists between the health worker's and patient's point of view. Those health professionals who assume the perspective of Parson's sick role theory perpetuate this discrepancy. As the dominant partner in the patient-provider transaction, the health professional retains absolute authority. However, as demonstrated, medical recommendations are evaluated by the patient on different terms. For this reason, failure of the health professional to recognize the patient's perspective occurs when the health professional believes he is viewed as an absolute authority.

Thus health professionals may be working against themselves if they cut off patient participation by assuming the traditional style of patient-professional interaction (this assumes a passive, dependent patient and independent, authoritarian professional). Ultimately the goal of the health professional is the improved health of the patient or at least the maintenance of the *status quo* (Di Matteo & Di Nicola 1982). If patients refuse to adhere to effective therapies, this goal will not be realized.

PROMOTING COMPLIANCE

The traditional approach to patient–professional interaction ignores the basic premise of the health belief model. That is, how the patient perceives the situation determines whether or not he will comply. The patient understands the regimen in terms of the way it will affect his life. The health professional understands the regimen in terms of the way it will affect the patient's health. However, to enhance compliance, a reorientation of the medical perspective is necessary. Understanding the patient's personal priorities will allow the health professional to determine how important the therapy is to the patient. The adolescent cystic fibrosis patient may prefer socializing with friends after school, rather than having chest physiotherapy. A diabetic child may have difficulty adhering to a diet when his siblings are allowed to indulge themselves in sweets. An emphysema patient, living on a second floor apartment, may prefer not return to his apartment for recommended treatments when he has already left home. Climbing the stairs requires just too much energy. This kind of information is useful for the health professional to know. This means patient input is required.

Promoting compliance in patients with chronic illness necessitates a greater degree of patient participation than that outlined by Parson's sick role. Both health professional and patient need to actively contribute to the relationship. The health professional provides medical knowledge. The patient provides knowledge about his background. Mutual exchange of information can lead to negotiation. In fact this type of provider–patient interaction has been described as contractual medicine (Di Matteo & Di Nicola 1982) or mutual participation (Szasz & Hollender 1956). Such a model of interaction facilitates the adaptation of a treatment to an individual's lifestyle.

A patient's lifestyle is evaluated by assessing his activities of daily living, such as dietary, sleep, exercise and rest patterns. Regimens can be modified to accommodate these patterns. For example, a diabetic's calorie intake may be controlled by reducing the amount he eats, instead of changing the kinds of foods he prefers. Assessing rest and activity patterns enables the health professional to evaluate when planned visits to a clinic for inhalation therapy may be too tiring for the limited energy of an emphysema patient. The patient may be accommodated by sending inhalation therapy equipment to the home. The usefulness of accommodating a regimen to an individual's lifestyle has been demonstrated in studies that link medication schedules to a person's daily activities (Becker & Maiman 1980). For example, Haynes *et al.* (1976), by matching medication administration times to habitual behaviours, among other strategies, improved compliance of hypertensive men significantly. Rather than changing the patient's timetable to accommodate medication ingestion, the medication schedule is adapted to the patient's routines.

In order to participate in decision making, the patient needs information. This may involve shaping the patient's perception of the severity of his condition or of the benefits of a recommended regimen. To prescribe a diabetic a diet without explaining why it is necessary provides little reason for adherence other than the physician said he should. However, by explaining the purpose of the diet the physician can alter the patient's understanding of the diet's benefits.

Patient education alone, however, does not appear to improve adherence (Haynes *et al.* 1979, Hogue 1979). Telling a patient why it is important to follow a treatment programme does not make the regimen any more adapted to the patient's lifestyle. Providing information is only one step in the process of facilitating patient participation and compliance.

A method which seeks to improve the patient–provider relationship and meets the criteria outlined above is the 'contingency contract'. Based on reinforcement theory, the contract provides rewards for behavioural objectives agreed upon between patient and health professional. Goals are designed, founded on education about the patient's diagnosis, health and treatment and the patient's specification of his priorities. The contract thus necessitates input from both patient and health professional. Decisions about treatment are mutually agreed upon. Allowing the patient to select his own reward increases patient involvement. Different people find different things rewarding (Steckel & Swain 1977).

Studies show that contingency contracting is effective on a short-term basis (Becker & Maiman 1980). Long-term effects have yet to be determined. Nevertheless, contingency contracting encourages patient participation in care and provides the practitioner with an opportunity to understand the patient's motives, demands and priorities, so that an appropriate regimen can be worked out. In addition specific well-defined goals are established and reinforcement for goal attainment is provided. Patient participation can include family participation because improved compliance is associated with a supportive family (Hogue 1979). Hogue advises asking the patient to identify major support persons. These people can then be included in discussions of the medical regimen. Such people may be able to suggest ways in which the patient may have difficulty complying. Sometimes family members are directly involved in managing regimens. For example, the wife of a diabetic may, as the household cook, be preparing diabetic meals. Involving these people in education is thus important.

Steckel & Swain (1977) effectively use patient education as an intermediate goal in attaining compliance with a regimen. Thus a patient is provided with pertinent information, a contract is negotiated and a post-test administered. This technique provides a significant increase in knowledge.

The strategies proposed centre around the idea that patient participation is necessary for long-term compliance to therapeutic regimens. This input must include information on the individual's lifestyle, so that health professional and patient can work together to provide the regimen which is the most likely to result in compliance.

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