The Issue Is

A System for Involving Patients in Program Planning

Various participants in the health care system are addressing humanistic issues such as consumer rights, ethics, and quality of life. One concern being addressed is a patient's right to participate in the planning of his or her treatment. Because a generic belief and responsibility of occupational therapists is the involvement of patients in therapy planning (American Occupational Therapy Association [AOTA], 1988), it would behoove the profession to examine its efforts in this area. Are occupational therapists involving patients maximally in planning activities and keeping pace with other professions and regulatory standards, or are they minimizing patient involvement and lagging behind current standards?

In this paper, we review some of the health care standards that require the involvement of patients in their own treatment planning. We also present a system for involving patients in planning and some initial results of the use of this system, which will ensure maximal patient participation and enable therapists to meet current standards.

Review of Standards

The following is not a complete review of all related standards, but rather, reflects a range of those standards concerned with patient participation. Included are standards of physical therapy and those established by various regulatory bodies.

Like AOTA, the American Physical Therapy Association (APTA) advocates patient participation. APTA (1985) expects its curricula to develop in physical therapy students competencies with which to elicit patients' cooperation with treatment and to individualize therapy. Further, the Standards of Practice for Physical Therapy (APTA, 1985) requires that the patient or significant other be included in the planning and revising of the therapeutic program.

Interest in and concern with patient participation extends beyond those persons involved in direct care to regulatory bodies. In its physical rehabilitation standards for hospitals, the Joint Commission on Accreditation of Healthcare Organizations (1988) requires that "the patient and the family participate as appropriate in the development and implementation of the treatment plan" (p. 180). The standards of the Commission on Accreditation of Rehabilitation Facilities (1988) echo the same ideal in the following statements regarding patient involvement:

II.B.5. The individual's program should be established, with his/her involvement, by those who participated in the evaluation. The goals of the person being served and the family when appropriate should be elicited and considered in program planning. (p. 31)

II.C.5.e. Assure that the person served or personal representative is involved on an ongoing basis in discussion of plans, goals, status, etc. (p. 32)

Among the rights of patients in nursing homes cited by the Commonwealth of Virginia is the "opportunity to participate in the planning of [their] medical treatment" (Virginia Code Commission, 1989, p. 212). The proposed rules for licensing private psychiatric hospitals in Ohio (Ohio Department of Mental Health, 1989) would require clinicians to actively involve patients in treatment planning and include in a treatment plan and revisions "the patient's involvement in and expressed concerns about the treatment plan" (p. 2).

Although these and other standards exist, we have noted that some clinicians have concerns about including patients in program planning, and some may not be optimally involving patients. In one in-service session in Richmond, Virginia, with approximately 50 occupational and physical therapists in attendance, 20 concerns about involving patients in planning were expressed. These concerns were related to four general topics: (a) setting realistic goals, (b) working with cognitively impaired patients, (c) motivating the patient, and (d) dealing with patient, family, and professional relationships. We also observed that therapists were surprised by the goals we elicited from their patients when we used a systematic interview process, described below. In some cases, we elicited goals based on pa-
patients' major concerns that were not being addressed in therapy. In other cases, therapists stated that they do not have the time to use such an interview process. On the basis of our limited observations, then, we question how effectively therapists are involving patients in program planning.

The Patient Participation System

Ozer (1980), a neurologist, developed a system whereby patients are actively involved in setting their own treatment goals. More recently, he added the patient as an evaluator of outcomes and a designer of his or her treatment (i.e., identifying effective treatment means). Because we are interested in the psychosocial aspects of illness and disability, we learned Ozer's patient participation process and jointly modified it so that it is compatible with our professions, that is, occupational therapy and physical therapy, respectively.

The Patient Participation System is a format with which one conducts interviews with a patient (Payton, Nelson, & Ozer, 1990). Four general questions are the basis for the format: "What are your concerns?" "What are your goals?" "What have you achieved?" and "What worked?" For each question, the therapist involves the patient in the processes of exploration, selection, and specification. The first two questions (i.e., concerns and goals) are addressed in an initial interview to establish a specific patient goal or goals. The last two questions (i.e., achievements and solutions) are addressed after the patient has participated in a period of therapy. After having the patient answer the last two questions, the therapist initiates a cyclical process by redirecting the patient to the questions of concerns and goals to establish new specific goals.

A key feature of the Patient Participation System is the use of four levels of patient participation. If therapists are truly concerned about getting patients to answer the above questions, guidelines are provided that permit patients to answer these questions at the highest level of which they are capable. The ideal level is one in which the therapist asks the patient the four open-ended questions described above and the patient responds using free choice. If the patient cannot function at the free-choice level, then he or she is involved at the next level, which is multiple choice. At the multiple-choice level, the therapist asks the patient the question and provides three possible answers. If the patient cannot respond at the multiple-choice level, he or she is involved at the next level, which is forced choice. At the forced-choice level, the therapist asks a question and offers an answer. The lowest level of participation is that of no choice, to which the patient may answer yes or no; here the therapist does not ask the patient but rather tells the patient what to do. The prescription of concerns and goals to the patient is not the desired level to use and will have negative consequences for patient motivation.

We support the use of the Patient Participation System for several reasons. First, we believe that health care consumers have a right to participate in planning their care. The Patient Participation System enables the patient the opportunity to participate in a meaningful way in establishing specific goals, identifying outcomes, and determining effective treatment means.

Second, the system is efficient in achieving outcomes, because it permits therapists and patients to work together on the same specific goals related to the same real concerns. These goals and concerns have been developed with maximal patient participation. Although this system may lengthen the evaluation and reevaluation process, the patients will be less likely to be discharged before their major concerns have been addressed.

Third, the system is an aid to treatment planning: it eliminates the guesswork. Individualized goals are established with the patient as the result of the systematic and cyclical interview procedure. The use of this system helps to avoid the establishment of goals through the use of diagnostic labels alone.

Besides the therapists' and patients' arriving at relevant goals, evaluating outcomes, and designing treatment, the patient experiences a goal-setting process, a learning situation that he or she can use after therapy is discontinued. This is especially beneficial for patients who are chronically and severely disabled, who will confront many new life-style changes.

Results of Application

Some examples of specific goals arrived at by the Patient Participation System will indicate its potential in the individualization of goals. A woman in her 60s being trained in the use of new lower extremity prostheses was interviewed. She reported that her major concern for 10 years, the time since her initial prosthetic training, was a fear of falling. A specific goal related to learning how to fall was established.

A young man in the rehabilitation phase of a cervical spinal cord injury volunteered to have occupational therapy students practice standard evaluations with him. After these evaluations were completed, he was asked about his concerns and goals. On the basis of his most important concern of feeding himself, he arrived at a specific goal of being able to independently eat a bowl of tomato soup at home. This had not been a specific therapeutic goal prior to the students' interviews.

A woman in her 30s suffering from chronic back pain agreed to have a physical therapy student use the system to interview her. The result was the establishment of the goal that the patient would be able to wrestle with her two children in her home without discomfort. The attending therapist was surprised that the patient expressed such a goal for herself.

We realize that other goal-setting methods may have resulted in these same specific goals or related general goals, however, in these cases they did not. We believe that the Patient Participation System enables the interviewer to more consistently elicit such personal goals.

The above cases demonstrate the power of this interview process in the identification of goals that are both functional and relevant to a patient's life-style. General goals such as mobility, independent feeding, and interaction with children are personalized by each patient to become such specific goals as learning how to fall, eating tomato soup, and wrestling with one's children.

Summary

Although standards exist that require occupational therapists and other health care professionals to include patients in the treatment planning pro-
cess, our observations lead us to believe that patient involvement is not being maximized. The Patient Participation System allows therapists to actively involve patients in a systematic goal-setting process. The initial results of the use of this system indicate that patients can be effectively involved in establishing personalized, specific goals; identifying outcomes; and evaluating treatment effectiveness.

References


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