Health Action Alliance: A Consumer Approach to Improving Ambulatory Care in a Family Practice Residency Clinic

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"The Health Action Alliance for Family Practice Clinic—St. Marys" is a group of physicians, patients, and clinic personnel who meet regularly for the purpose of providing a forum for interaction between health care personnel and patients. The group deals with patient training for effective participation in general clinic activities, participation in decision making processes of the clinic, health education, and other topics as the group decides. This paper discusses the formation of the group, its purposes, accomplishments, and plans for the future.

"The Health Action Alliance for Family Practice Clinic—St. Marys" was the name chosen by the members of the group of physicians, patients, and clinic personnel who have been meeting regularly since April 1975. The organization is a rather loosely knit group of persons whose major goals are to improve Family Practice Clinic—St. Marys as a place to obtain general medical care, from the patient's perspective; as a place to obtain training in the specialty of family practice, from the resident's perspective; and as a place in which research in family medicine can be accomplished, from the residency faculty's perspective. This paper discusses how the Alliance came into being, projects which have been completed, and plans for the future.

Background

Patients are not the only "consumers" of health care. Various persons acting as health care providers are also, from time to time, "consumers" of health care, whether they wish to acknowledge that role or not. From a broad viewpoint, meals that are eaten, toothpaste and soap used, automobiles driven, and lakes which are used for recreational purposes are all being monitored by various agencies concerned with health protection. At times, various groups complain about the government being too much of a "Big Brother," and about the over-regulation of society, but such regulations are designed to provide the environment for maintaining good health. As a consumer, there is often little that one can say or do in a direct manner regarding these regulations. Therefore, any opportunity which provides direct involvement in one's own health promotion should be encouraged. Unfortunately, much basic knowledge in health matters comes from advertising designed to promote specific products rather than as general information for improving basic health needs. There are many consumer groups working on a state and national level to safeguard personal and natural ecology, but except for donating money to such groups, one seldom becomes directly involved.

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The Health Action Alliance

A need for greater patient involvement as perceived by the Department of Family Medicine and Practice of the University of Wisconsin Center for Health Sciences led to requesting a group of consumers of medical care at one of the ambulatory care clinics to assume a direct responsibility for the manner in which that clinic operates. During the Department's early organizational years, a series of lectures concerning medical topics was provided for a group of patients. This series was quite successful in terms of continuing attendance, but was entirely directed at patient education in the general aspects of medical care and provided no involvement by the patients in productive input regarding clinic policy. Subsequently, members of the department faculty decided to experiment with one of the three Madison-based ambulatory clinics by organizing a patient advisory group to provide feedback to the clinic directors in an effort to improve clinic operations from the patient's viewpoint. This was the beginning of the Health Action Alliance. Of the department's three Madison-based ambulatory clinics, Family Practice Clinic—St. Marys was chosen as the clinic to sponsor the original group.

The 12 original patient members were solicited by general letters of invitation which were sent to approximately 700 families registered at the clinic. No interested persons were excluded. Meetings were scheduled twice a month and held in the clinic waiting room. The Clinic Medical Director, Department Medical Educator, Clinic Business Manager, several resident physicians, and occasional medical students joined the 12 patients to comprise the group, and together they decided on the following beginning goals and objectives:

1. Information service
   A. Regular and/or periodic communication to patients regarding clinic services
   B. Information to assist the patient in making an informed choice regarding medical and surgical management
   C. Information to clinic and department directors about patient needs and wants
   D. Information about current and pending policy decisions of the department and clinic faculty
2. Patient training for effective participation in clinic activities
3. Patient participation in the decision making processes of the clinic
4. Simple and clear complaint procedures that include the earliest possible response with timely recourse to the highest levels
5. Health education
   A. Education for prevention of illness
   B. Education for best utilization of the services of the clinic
   C. Education for health betterment
6. Establishment of minimum standards for the facilities (privacy, comfort, and convenience)

The first major project was that of formulating a written statement with the title, "Mutual Goals and Responsibilities for Health Care between Patients and Physicians of the Family Practice Clinic—St. Marys of the Department of Family Medicine and Practice of the University of Wisconsin Center for Health Sciences." The process by which this document was formulated was long and arduous, with subcommittees composed of patients and physicians meeting frequently in an attempt to guarantee the rights of each group, while still providing the necessary learning opportunities for the residents in family medicine. An example of a difficult section of the document was that of the right for confidentiality on the part of the patient when there is a need to discuss the patient's problems in seminars, in order for the resident physicians to best learn how to practice family medicine. The final document is one in which the Alliance takes a great deal of pride, and one which both the health care providers and health care consumers can use as a basic guide to rights and responsibilities (Appendix 1).

The second major project was the provision of an information booklet for use by the patients of the clinic. This booklet includes an introduction explaining the three purposes of the clinic, ie, service to patients, teaching of residents and students, and research opportunities for improved methods in outpatient care. A second section lists basic first-aid hints for 27 common health problems, and the third section includes ideas for health promotion. The fourth section is a copy of the "Mutual Goals and Responsibilities." The booklet is printed so that it can easily be slipped into a common business envelope.

During the past three years, the Alliance has

attempted to fulfill the original goals and objectives. Information regarding the clinic and the activities of the Health Action Alliance has been documented by a patient acting as scribe and posted in the waiting room on a special bulletin board. Group discussions have dealt with the topics of informed choice about reasonable alternatives of care, feedback from the patients regarding what they like and what they do not like about clinic operations, and educational meetings about the ethics of medical practice, the medical needs of the city of Madison, and psychological counseling using behavior modification and medical hypnosis. A nonmedical member of the Alliance is a permanent member of the Executive Committee of the clinic, thereby adding the patient viewpoint to decision making. This person is an active committee member with full voting rights. He/she reports information regarding operation of the clinic to the Alliance. A subcommittee has been active in decorating the waiting room and reception area, and a new subcommittee is being formed to aid Madison hospitals in their desire to offer alternate methods of obstetric care. A second new subcommittee is involved with the formation of parenting groups to deal with the problems in the birth to five-year-old range, including how best to develop coping mechanisms to help prevent maltreatment of children.

Since the original organizational meetings with the 12 patient members, the Alliance has varied in size depending primarily on the needs of ongoing projects. Patient participation has varied from a high of 12 to a low of six active members, although notices of meetings and minutes are being sent to about 30 members. New members are solicited by direct contact by resident and faculty physicians as well as through notices in the patient waiting room, and occasional general notices through direct mailing and the billing system. The most successful method of obtaining new members seems to be direct invitation by the attending physicians, with subsequent telephone follow-up prior to the next scheduled meeting. The concept of a group of physicians seeking input from health care consumers is quite foreign to most patients, and therefore, detailed information regarding the concept of the Health Action Alliance, its purposes, and its plans, must be provided to the patients. Successful continuation of the Alliance has demanded ongoing reevaluation of the purposes as well as reinforcement of the value of the Alliance to both the participating patients and the clinic personnel. At this writing, the Health Action Alliance continues to be a vital and integral part of Family Practice Clinic—St. Marys.

The original Health Action Alliance was physician stimulated and physician motivated, with the patients being passive participants. After six months, when the organization was well established, there was a gradual change of emphasis with more originality of ideas by the patient members. Although no constitution or bylaws have been written, the group has elected a chairperson and a scribe to organize meetings, prepare agendas, and provide minutes of each of the meetings. On occasion, the professional participants have provided lists of suggested topics from which the group as a whole has chosen projects, learning experiences, and areas of clinical involvement. Several social gatherings, such as picnics and parties, have been arranged by the patient members.

The total effect on the clinic has been difficult to evaluate since the clinic and the Health Action Alliance were developing concurrently. Comparing Family Practice Clinic—St. Marys with the other two clinics in the Madison program has been difficult because of the many variables in clinic design and operation. It is of note that the clinic at St. Marys was the only clinic with a patient as an active member of the Executive Committee, and the only clinic which has provided for direct resident-patient encounters other than in the specific treatment settings, until a second of the three clinics developed a similar group in November 1977.

Although the Health Action Alliance at Family Practice Clinic—St. Marys was physician stimulated and physician motivated, the Health Action Alliance which began at Family Practice Clinic—Northeast was patient motivated and patient stimulated. A specific patient from Family Practice Clinic—Northeast transferred her family's care from St. Marys to Northeast. She was so stimulated by the Alliance concept that she spoke with her specific resident physician and several other patients who then organized the Health Action Alliance at Northeast Clinic. That group is oriented primarily toward patient education, particularly in areas of training in child-rearing techniques, and has had several parenting effectiveness seminars.

Appendix 1

Mutual Goals and Responsibilities for Health Care Between Patients and Physicians of the Family Practice Clinic— St. Marys of the Department of Family Medicine and Practice of the University of Wisconsin Center for Health Sciences

General Philosophy: Health care involves close personal communication and cooperation. Thus both providers and recipients are entitled to consideration, honesty, and respect.

I. Mutual Responsibilities for Health Promotion and Health Care.

A. The patient's participation in his/her own health care is necessary even though he/she has asked a physician's help.
B. The physician has the obligation to provide the patient with enough education and technical help so that the patient can participate positively in his/her own health care.
C. The physician has the obligation to keep his/her knowledge current regarding information in the medical care field and to provide up-to-date high quality medical care.
D. Both the physician and the patient should realize that medical science cannot alleviate all physical and psychological problems. However, the patient should feel free to report unusual symptoms and problems which are worrisome.
E. The patient has the right to know his or her financial responsibility for care.

II. Communication Responsibilities of Both Patient and Physician

Physician's Rights	Patient's Rights
A. The patient or person acting in his/her behalf has the obligation to give the physician accurate and succinct reports about his/her symptoms (and those of their children) and to reveal all information necessary for reliable diagnosis and health care.	A. The physician has the obligation to give the patient full and complete information concerning the diagnosis, medical problem, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to the appropriate person.
B. The physician has the right to know the patient's full and correct name and who else, if anyone, is responsible for his/her health care.	B. The patient has the right to know by name the physician responsible for coordinating his/her care. The patient also has the right to know the educational status of the physicians or students attending to his/her health care and their possible relationship to other health care and educational institutions.
C. The physician has the right to express his/her concerns regarding the patient's compliance with the medical advice.	C. The patient has the right to express his/her concerns, questions, criticisms, feelings, and satisfactions or dissatisfactions to his/her physician with respect to the diagnosis, care, and treatment he/she receives.

Appendix 1, continued

III. The Right to Establish the Physician-Patient Relationship

Physician's Rights	Patient's Rights
A. The physician has the right to refuse to accept a patient except in an emergency. If the physician wishes to terminate an existing relationship, he/she must give adequate time for other arrangements to be made for the patient's medical care and assist in orderly transfer.	A. The patient may have the physician of his/her choice when practical, and may change physicians when desired.
B. The physician has the right to know why the patient changed to another physician.	B. The patient has the right to know why a physician has refused care.

IV. Treatment/Procedures

Physician's Rights	Patient's Rights
A. The physician has the right to receive feedback from the patient concerning his/her understanding of the physician's explanations and directions.	A. The physician has the obligation to provide the patient, or the appropriate person in his/her behalf, with information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include, but not necessarily be limited to, the specific procedures and/or treatments, the medically significant risks involved, and the possible duration of incapacitation, what medically significant alternatives for care or treatment exist, or when the patient has the right to such information. The patient also has the right to know the name of the treatment.
B. See "A" above.	B. Patients have a right to be informed about reactions which may occur during medical treatment and procedures.
C. The physician has the right to know if and why the patient has decided not to accept the prescribed treatment.	C. The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his/her action.

V. Privacy/Confidentiality

Physician's Rights	Patient's Rights
A. As St. Marys Clinic is a teaching institution affiliated with the University of Wisconsin Medical School, the physician has the right to use individual records and case discussions for educational and professional use; but the patient's right to privacy should guide the manner in which individual records are used.	A. The patient has the right to every consideration of his/her privacy concerning his/her own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted as discreetly as possible.

Appendix 1, continued

Physician's Rights	Patient's Rights
B. The physician has the right to advise that a patient not be admitted access to his/her medical records if the physician believes the material contained in the records would have a negative effect on the patient's health care.	B. The patient has the right to review with the physician his/her complete medical records.
C. The physician has the right and obligation to report all illnesses and conditions as required by law.	C. The patient has the right to have his/her records held in confidence unless a specific signed release of information has been provided. The exception is reporting of certain illnesses and conditions as required by law.

VI. Consultation/Referral

Physician's Rights	Patient's Rights
A. Physicians have the right to expect that the patient will express his/her desire to have another physician's opinion or consultation and to be informed when other health care providers are consulted.	A. The patient has the right to have other medical opinions and medical consultations when desired.
B. The physician has the right to consult another health care provider when he/she feels it is in the best interest of the patient.	B. The patient has the right to choose the specific consultant when an area of consultation has been suggested
C. Physicians who act as consultants have the right to have access to the medical records of their patients. If the patient withholds records, the primary physician has the obligation to inform the consultant that the medical record being sent to him/her is incomplete.	C. The patient has the right to withhold permission to transfer his/her medical records to another health care provider. The patient would then be responsible for any medical consequences of his/her desire to withhold medical information.

VII. Ethical Considerations

Physician's Rights / Patient's Rights

A. The physician and patient have the obligation to show mutual respect for each other's moral and religious beliefs.

Physician's Rights	Patient's Rights
B. The physician has the right to be informed of the patient's moral and ethical beliefs with respect to the patient's health care.	B. The patient has the right to be advised of treatment alternatives for his/her health care without limitation by the physician's ethical beliefs.
C. The physician has the right to request that the patient participate in an experimental program.	C. The patient has the right to be advised if anyone proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to

Appendix 1, continued

Physician's Rights	Patient's Rights
	participate in such experimentation. The patient has the right to be told about proposed filming or recording of an encounter, observation through the one-way glass, or any other third-party involvement, and to deny permission if he/she wishes.

VIII. Availability

Physician's Rights	Patient's Rights
A. The physician has the right to know whether the patient considers the clinic as the primary source of his/her health care, and if not, who the primary source may be.	A. The patient has the right to expect reasonable continuity of care.
B. The physician has the right to expect the patient to notify him of all medical problems within the family.	B. The patient has the right to know in advance what appointment times and physicians are available. The patient has the right to be informed when his/her physician will not be in the clinic for an extended period of time and to be told of other physicians who will care for them during this time. This information is available on patient request.
C. The physician has a right to leisure, private life, and rest.	C. The patient has the right to medical care at all times.

D. The patient and physician have mutual obligations to make appointments and keep them unless notified ahead of time.

Evaluation of the overall effect on the medical care system, physician-patient relationships, compliance, broken appointments, etc, has not been accomplished. Such evaluation is in the planning stage and will need further time for implementation.

Discussion

Since the Health Action Alliance concept as presented in this paper is part of a family practice residency program, it is not directly applicable to the practicing physician. However, the idea of involving consumers in policies and operating procedures is applicable to any clinic setting. The learning environment of a residency clinic is stimulating to patients because of the need for innovation in correlating service functions and learning functions without detriment to either of them. As an example of this interest, several nonmedical members have agreed to become the patient component of video taped physician-patient interactions as a teaching and evaluation modality. One of the younger members has entered the University of Wisconsin as a premedical student partly on the basis of her interest in the discussions with the residents. The application of the concept of the Health Action Alliance to a practicing physician's practice or to the practices of a group of physicians involves a somewhat different set of goals. Emphasis would be toward the education of the patient regarding basic health care and an understanding of risk factors and their avoidance. Such a group would also be helpful in aiding the physi-

cian to more fully understand his or her own practice particularly from the patient perspective. Several of the purposes outlined earlier (such as the dispensing of information about the office to patients, the involvement of patients in decision making regarding credit policy, office hours, office decor) would pertain in the private physician's office, but activities regarding students and residents would be lacking. There are several such groups currently functioning in private physicians' offices, and more experimentation with the concept is needed. Perhaps as the interest in self-care and a greater understanding of simple health problems develop, groups of health care providers and consumers might wish to initiate such alliances and perhaps become organized on a state or national basis to further the concept.

In summary, a group of patients of Family Practice Clinic—St. Marys ranging in age from 17 to 71 have been meeting monthly for the past two years with physicians and health care personnel. The "Health Action Alliance for Family Practice Clinic—St. Marys" has remained an interested and productive group of health care consumers and providers acting as role models for the physicians in training to improve ambulatory health care. A more recent group at Family Practice Clinic—Northeast has developed because of a specific patient's interest. The goals have been reasonable and are being accomplished, and the outlook for the future is excellent. Similar groups associated with residency clinics or practicing physicians may aid in improving health care in the future.