

Ileostomy and Colostomy Support Groups

ALBERT S. LYONS, M.D.

Abstract

The first organized ostomy support group in the world was formed at The Mount Sinai Hospital, in 1950, through the efforts of a surgeon and the patients themselves. Later, similar groups were set up in other locations and some even took the name of Mount Sinai's first such society (QT).

These groups had two major functions:

- Psychological: reassurance and understanding from other ostomates before and after the operation; advice on how to deal with oneself and others.
- Educational: instruction on the details of stoma management; information for surgeons on the proper location and other details of fashioning a stoma; information to the public on the existence and needs of ostomates.

In order to extend services to more people and with more individual attention, a special clinic was established at The Mount Sinai Hospital devoted entirely to patients with ileostomy and colostomy. It too was the first of its kind anywhere.

Years later, two surgeons arranged an all-day convention of the ostomy groups in the greater New York City, New Jersey, and Connecticut areas, at the New York Academy of Medicine. At the convention, the idea of a national society was conceived. In the following years — in Detroit, then Cleveland, and finally Los Angeles — the United Ostomy Association was developed, structured, and incorporated.

The educational uses of the ostomy groups were later supplemented and partly replaced by enterostomal therapists who originally were trained and practiced in Cleveland. Now the therapists, the societies, and the ostomates themselves are available to patients with various types of stomas, whether recent or longstanding, before and after surgery.

Key Words: Ileostomy, colostomy, patient groups.

IN 1949, FOUR PATIENTS with ostomies met at the Veterans' Hospital in Valley Forge, PA, as did others in 1949 and 1950, in New York City and elsewhere. But these were occasional, spontaneous, mainly social get-togethers of two, three, or four persons with ileostomies or colostomies. The first formal, organized ostomy support group in the world began at The Mount Sinai Hospital in 1950; in 1952 I reported the earliest meetings of this group (1). The monthly meetings were attended by patients who had had ileostomies for the treatment of ulcerative colitis on the ward surgical service and other services, and at other hospitals. The meetings had their origin in a small social gathering at the home of one of the eight women patients who had come to know each other as patients in the hospital. It became clear that these

patients had a most valuable idea which needed some nurturing. Both Miss L.M. Neary, a social worker assigned to the surgical service, and I set out to encourage these efforts.

Since the patients were admitted to Wards Q and/or T, the new group called themselves "QT Alumni." The choice of the term "QT" avoided using the word "stomas." Elsewhere, other groups began to form. For instance, in recognition of the fact that the pioneering work was done in New York, the Boston group called themselves QT Boston and the Detroit group, QT Detroit. Years later, people no longer felt it necessary to use the term "QT" and groups became known as ileostomy, colostomy, or ostomy associations (2).

In a 1987 interview with Hall (2), I described how I helped supervise the early meetings. My chief, Dr. John Garlock, was most helpful and encouraging. Because of his influence in the hospital, I was able to get support that I might not have gotten otherwise. My colleagues and co-workers, and others in the institution, were also favorably impressed. Ultimately, the group became larger and began to function by itself.

From the Department of Surgery, Mount Sinai School of Medicine, New York, NY.

Address correspondence to Albert S. Lyons, M.D., Emeritus Professor of Surgery, 88 Central Park West, New York, NY 10023.

Shortly after we started the ileostomy group, I thought we ought to start doing the same for people with colostomies. The first colostomy meeting, however, was discouraging. In the ileostomy group, there were a couple of very enthusiastic and remarkable young women and men who took responsibility and helped make the group possible. Unfortunately, the colostomy group did not have enough members willing or able to do likewise. Therefore, I didn't have another meeting until some years later, when three patients with colostomies met with my surgical colleague, Dr. George Schreiber, and me. They said that they wanted to form a group which included people who were willing to become involved (2).

The benefits derived by the patients in The Mount Sinai Hospital groups and elsewhere may be classified as psychological and educational.

Psychological. Enormous reassurance and support was received by the interaction of individuals with the same conditions, when they had the chance to discuss their feelings and how they dealt with family, friends, fellow-workers, and society at large. Also, the experiences of ostomates were enlightening to each other, notably on sex, pregnancy, occupation, and leisure activities. Patients have frequently said that their entire attitude changed when they were visited in the hospital by a club member. Some who had been unable or reluctant to properly manage their own stoma care after leaving the hospital came to accept their involvement in their own care. Moreover, even the well-adjusted person of long-standing club membership found an added meaning to his or her life by serving as an "expert" to help the neophytes (1).

Among the most useful contributions were visits by an ostomate member to patients before and/or after operations. Patients often reported that these visits transformed uncertainty to optimism. Instead of fear of "abnormality" because of the stoma, patients cheerfully adapted to a procedure which restored their health.

Educational. Information and even instruction on the management of ileostomy, colostomy and urostomy were provided by fellow patients, as well as by doctors and nurses who came as guests or advisers. Details were also provided about the specific types of appliances available, and the advantages and requirements of each. Before the advent of enterostomal therapists (ET), this technical advice was sometimes the principal source on which the ostomate could depend, since many doctors and nurses had limited experience in the details of stoma care and control.

Both patients and surgeons learned much at these meetings. For instance, the patients' recital of difficulties often indicated to the professional how to plan the stoma and its location before the operation, by taking into account particular anatomical and functional requirements of each person. When the enterostomal therapists came upon the scene, the needs of particular people and the resolution of difficulties were highly instructive to all parties. Moreover, the local groups working together could educate and influence the public, whereas individual patients, concerned about their privacy, were less likely to "reach out."

The Intestinal Rehabilitation Clinic

The ostomy group at Mount Sinai originally met in the evening in a clinic waiting room. Various problems were discussed, and then I, or somebody else, would talk. At the end of the meeting, the people would line up, and I would discuss their particular problems, one by one. I was joined later in this enterprise by Dr. George Schreiber, who had been a resident at Mount Sinai and then an attending (2, 3).

Attendance at meetings of the ileostomy club was about 15 at first; then it increased to more than 50, and sometimes to well over 100. The colostomy group, which met separately, also grew rapidly, making it impossible to deal with the special problems of individual people. In the late 1950s, I appeared before a committee of the Board of Trustees, headed by the president, Joseph Klingenstein, to request a special clinic devoted entirely to persons with external intestinal stomas. Soon afterward, the Trustees agreed. This "Intestinal Rehabilitation Clinic" was the first of its kind in the world. It was staffed voluntarily by myself, Dr. George Schreiber, Dr. Bernard Robinson, and Dr. Robert Turrell, a proctologist who would later found the Society for Surgery of the Alimentary Tract (at first, it was named the Society for Colon Surgery). A registered nurse, Miriam Jacobson, who was Robinson's office nurse, acted as the clinic nurse.

At that time, there was no clinic other than the one at Mount Sinai devoted solely to the care of stomas. At the Massachusetts General Hospital in Boston, and at other sites, there were follow-up clinics used by the surgical staff just to keep track of the postoperative patients.

The United Ostomy Association

In 1956, QT New York invited the known existing ileostomy and colostomy groups to

share their experiences. Representatives from eight ostomy groups (six ileostomy and two ileostomy-colostomy) throughout the U.S. met there. Some attended with the idea of forming a national organization (4).

As a result of this meeting in New York, *Ileostomy Quarterly* and *Colostomy Quarterly* were created. The colostomy publication appeared only once, but the *Ileostomy Quarterly*, sponsored by QT Boston and edited by Edith Lennenberg, continued on a regular basis. In New York, Leon Berger put together a monthly bulletin, *QT New York*, which was mimeographed. Later, formally printed monthly bulletins were sent out by both the ileostomy group and the colostomy society.

In 1960, QT New York sponsored a workshop at the New York Academy of Medicine, to which all existing ostomy groups in the U.S. and Canada were invited (2, 4). There were presentations by patients and panel discussions by surgeons, internists, gastroenterologists, and psychologists. Afterwards, the people who came from the various clubs sat down with us and asked if it was possible to make something of this that extended beyond just the local area. We all thought it was a very good idea.

In 1961, a meeting was held in Detroit. I could not attend, but I was in touch by telephone with several people there, and learned that there was intense disagreement. I remember sending a telegram to one attendee, saying that if the thirteen colonies could get together and form a union, I hoped that people who had a common purpose could act together and forget geographic differences and other personal needs. I do not know whether the telegram had any effect at all, but I do know that the decision was made, at that meeting, to meet in Cleveland subsequently. During that interval, various working parties met to facilitate the founding of the new national organization (2).

At the Detroit meeting, a committee on a constitution and bylaws had been established. In 1962, delegates from 24 groups assembled in Cleveland, Ohio and set up the structure for the United Ostomy Association.

In Los Angeles, in 1963, the organization was officially and legally established and its first officers elected. *The Ostomy Quarterly* appeared in December 1963, under the editorship of Virginia Pearce — who introduced the term “ostomate” into the medical literature, taking it from Egon Orawan, an engineer at MIT who was interested in perfecting a superior ostomy appliance. He coined the word “ostomate” by

combining the suffix “ostomy” with the term for a person, “mate” (2). Until then, various other terms had been used, such as “stoma person,” “ostomite,” and even “person with an ostomy,” but “ostomate” became and remained the standard term thereafter. An international Ostomy Association was established in 1975, principally because of the dedicated work of Vinitzky (4).

Norma Gill (5), under the aegis of the surgeon Dr. Rupert Turnbull in Cleveland, developed the concept of specifically trained professional therapists for ostomates. Thus, she was the first enterostomal therapist. At Mount Sinai, Marlene Brockmeier, and then Sally Bishop, both registered nurses, followed this pioneering work of Gill and Turnbull.

Ever since these pioneering efforts, the technical knowledge and advice for ostomates have been provided by enterostomal therapists, most of whom are nurses, some of whom have had stomas themselves. They have been specifically trained as professionals to teach, care for, and advise patients and doctors on the management of stomas. ETs (as they are usually referred to) often give instruction and advice at the ileostomy and colostomy meetings. Indeed, they themselves still learn from the ostomate groups. But the psychological and educational functions of the ostomy groups continue as before.

Perhaps the most important result achieved by these support groups has been their demonstration, by living example, that a person with a stoma can lead a healthy, happy life filled with all the joys and activities of “normal” people (1). In 1987, at a convention of enterostomal therapists, in response to a question on the continued usefulness and effectiveness of the ostomy groups, I characterized the need felt by ostomates for the ostomy societies as follows:

No land of birth nor right of name
Shall claim my family line,
But he and she who share my pain
Are brother, sister mine.

References

1. Lyons AS. An ileostomy club. *JAMA* 1952; 150:812–813.
2. Hall TBM. Reflections of a founder. Interview. *Ostomy Q* 1987 Summer; 24(3):27–32.
3. Lennenberg E. Tribute to Dr. Schreiber. *Ostomy Q* 1988 Spring; 25(2):39.
4. Anderson L, Vinitzky A. Creation of the UOA. *Ostomy Q* 1987 Summer; 24(3):8–9.
5. Gill N. Mother of enterostomal therapy spawns schools nationwide. *Ostomy Q* 1982 Fall; 19(4):16–17.