**¹The Value of Support Groups as Part of the Rehabilitation of the Ostomy Patient**

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I have had the privilege and opportunity of caring for patients requiring surgeries for a variety of conditions, including colorectal cancer, trauma, intestinal blockage and inflammatory bowel disease such as ulcerative colitis and Crohn’s disease as well as other gastrointestinal conditions for nearly four decades. In many cases, my patients undergoing such surgeries have required ostomies, some of which have been on a temporary basis and others on a permanent basis. As a surgeon, I have learned and have appreciated early-on that the care and management of my patients requiring an ostomy involves a team effort, beginning with preoperative education and continuing with the actual surgery and postoperative recovery and then the adaptation to the changes that the patients face in having an ostomy. In this article, I will focus on the evolution and the importance of support groups such as the Winnipeg Ostomy Association and the Ostomy Visitor Program as part of the rehabilitation of the ostomy patient.

The first known ostomy support group began as an informal meeting of ostomy patients in 1949 in the United States at the Valley Forge Hospital near Philadelphia. This was the first time that ostomates were able to share their experiences and concerns related to their ostomies. Moreover, they were able to seek advice and find solutions to many of those problems. Most importantly, they found mutual support as a group¹.

The first formally-organized ostomy support group was established in 1950 at the Mount Sinai Hospital in New York due to the combined efforts of a surgeon, Dr. Albert S. Lyons, a hospital social worker and a number of Dr. Lyons’ patients. The Ostomy Support Group was entitled: QT New York. This group’s function was twofold: 1. psychological support for reassurance and understanding from other ostomy patients and 2. Educational instruction on stoma management and information to the public regarding the concerns of ostomates. Within a matter of months following the establishment of QT New York, members of the group were visiting new ostomy patients in the hospital. Thus, the Ostomy Visitor Program began².

It didn’t take long for new Ostomy Support Groups to be established in other cities in the United States, in Canada and in Europe. The Winnipeg Ostomy Association (WOA) was established in 1972. It is a volunteer organization that provides assistance and education to ostomates in Winnipeg and other parts of Manitoba. The WOA is affiliated with the national organization, The Ostomy Canada Society.

Since their inception nearly seventy years ago, Ostomy Support Groups, including the Winnipeg Ostomy Association have evolved in terms of their organization and function. Today, the WOA offers emotional and educational support to ostomates and their families through regular chapter meetings where members and often health care professionals are able to discuss topics on a face-to-face basis. The WOA publishes and distributes to members the informative print-version newsletter, Inside Out which covers different ostomy-related topics, new products and resources for ostomates as well as other tidbits of information, including social events and family related news. The WOA has hosted national conferences and has held many social events for ostomates and their families. The WOA has kept instep with the advances into the digital age through the development of a web-based interface with members and an email members’ blog. In addition to support of ostomates, Ostomy Support Groups function to disseminate important information to the public in order to promote “ostomy awareness”.

An extremely important function of the Ostomy Support Groups such as the WOA is the provision of the Ostomy Visitor Program, where a person with an ostomy undergoes training and is certified through the local Ostomy Association Chapter. The ostomy visitor is a valued member of the team that provides support to patients who are about to undergo or who have recently undergone ostomy surgery. The patient must adapt to changes in bodily function and altered anatomy and body image. The ostomy visitor through a sharing of his or her own experiences can provide important information that perhaps nobody else is able to provide.

There are many wonderful and heartfelt testimonials written by ostomates, describing how important it was for them to receive the educational and emotional support from their Ostomy Support Group and from the Ostomy Visitor who provided the invaluable “voice of experience” so that the patient who was about to receive or who had just received an ostomy felt supported during this journey.

In addition to the personal testimonials to the importance of Ostomy Support Groups, there has been research directed to reviewing the value of Ostomy Support Groups as part of the rehabilitation of the ostomy patient. For example, Edith Lenneberg, an ostomate and founder of the Boston Ostomy Association and an editor of the publication, Ileostomy Quarterly conducted a research project (1958-1962) in which she pondered the notion of the value of Ostomy Support Groups and she concluded that “ostomy and other mutual-help groups are the outgrowth of the increasing participation of the (American) public in matters of physical and emotional well-being… a healthy effort at self-help toward the ultimate goal of…maximal selfdependence”³.

Dr. William Markel, then Vice President for Service and Rehabilitation for the American Cancer Society addressed the American Society’s Second National Conference on Cancer of the Colon and Rectum in September 1973. The topic of his address was: The Ostomy Program of the American Cancer Society. In his presentation, he discussed the value and important contributions of the Ostomy Support Group at the time, the United Ostomy Association and provided statistics related to ostomy volunteer visitors and the fact that “there is increasing utilization of the volunteer visitors’ talents”4.

More recently, a research study from the University of Minnesota compared hospital readmission and emergency room visit rates related to ostomy complications between patients enrolled in a volunteer Ostomy Support Program as an adjunct to nurse-led ostomy care following discharge from hospital and those who did not have access to an Ostomy Support Program. The study demonstrated that the Ostomy Support Program reduced the likelihood of hospital readmission rates and emergency department visits due to ostomy-related complications5.

Interestingly, a study published in the Journal, Nursing Research demonstrated that ostomates who were members of an Ostomy Support Group and who volunteered as ostomy visitors demonstrated a greater acceptance of their ostomy than those members of an Ostomy Support Group who had not served as ostomy visitors6. This is truly an added benefit of the Ostomy Support Group: helping the helper. Ostomy Support Groups such as the Winnipeg Ostomy Association will continue to play a vital role in educating, supporting and advocating for patients and their families and in assisting health care providers as part of the team in restoring health and confidence to our ostomy patients.

I would like to thank the Winnipeg Ostomy Association for allowing me the privilege of being physician advisor.

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