It Takes a Village to Improve Care

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Nothing truly valuable can be achieved except by the unselfish cooperation of many individuals. — Albert Einstein

The first title of this journal, launched in 1980, was Ostomy Management. Reading the research about living with a stoma in the current issue of OWM, it may be difficult to believe 56 years have passed since Dr. Rupert Turnbull, the father of enterostomal therapy, enlisted patient Norma Gill to help his clients at the Cleveland Clinic in Ohio. At that time, most persons with a stoma developed their own solutions to manage the effluent and maintain skin integrity. Rubber appliances and cups, held in place with belts and/or very strong adhesive compounds, were available, providing one had access to them. But most appliances were jerry-rigged by persons with a stoma or by someone in their families. It has been observed that before the 1960s, ostomy construction suffered from poor surgical techniques, stoma care suffered from lack of nursing infrastructure, and ostomy product development suffered from limited technology and resources.\(^1\) As one ileostomy patient noted, “Post surgery in the hospitals was a nightmare of malodors and skin breakdown. The odors emanating from the absorbent dressings destroyed any vestige of ego and self-worth. The discharge digested the skin around the stoma, creating an inflamed, weeping, and painful situation.”\(^1\)

Much changed during the 1960s and 1970s. Norma Gill and Dr. Turnbull began educating nurses and surgeons in the United States and all over the world. In 1968, during a meeting of the United Ostomy Association, the American Association of Enterostomal Therapists (AAET) was born, and in the summer of 1974 the first issue of ET Nursing — now known as the Journal of Wound Ostomy and Continence Nursing — was published. In 1978, representatives from 32 countries met in Milan to constitute the World Council of Enterostomal Therapy (WCET). As Priscilla Stevens, SRN, ET, Past President of WCET, observed, “Many of these representatives returned to their countries to wage battle with administrators and sometimes medical and nursing personnel.”\(^2\) Only a few hospitals in a small number of countries had formalized stoma therapy care.

I was at the 1978 meeting and volunteering to be the representative for my country, The Netherlands. Convincing hospital administrators these patients needed and deserved specialized care, convincing payors the new disposable (!) equipment was indeed to be disposed of, and trying to convince regulatory and accrediting authorities that nurses should not have to travel to a different country (at great expense) to receive a formal education was almost a full-time job. At that time, only three or four of us in the country were employed full time as ET nurses. We all worked in large academic settings (>1,000 beds), saw a steady stream of outpatients with reusable and self-made appliances (and resultant prolapses and hernias), and were able to do what we did because the heads of the department of surgery, urology, or gastroenterology and the directors of nursing worked together to create (and pay for) the position. We received a great deal of assistance and referrals from the ostomy association and pharmacists. Nurses interested in providing better care volunteered to learn as much as they could and take on the extra responsibility of being the ET nurse for a hospital or visiting nurses association.

Through national and international networking and cooperation among ET nurses, physicians, patients, and industry, many improvements in care occurred all over the world. We even had skin barriers that actually could be applied to irritated skin. What a godsend for patients! Across the globe, ET nurses developed education programs, and networking — greatly facilitated by the Internet — continues to this day. The need to provide evidence-based practice is increasing substantially and, as demonstrated by several studies examining patient quality of life in this and previous issues of OWM, the beliefs and actions of Dr. Turnbull and Norma Gill-Thompson have been validated and proliferated. The education provided to persons with a stoma profoundly affects life after stoma surgery. Another equally important lesson they taught, since confirmed through research, is that cooperation benefits us all but especially the patient — not “just” inter- or intra-disciplinary care, but also across-the-board and across-the-globe cooperation with every stakeholder.

Clinicians caring for persons with ostomies have big shoes to fill as we follow in Dr. Turnbull’s and Norma Gill-Thompson’s footsteps to move patient care forward. We also have many more resources in terms of people and tools at our disposal. Although the quality-of-life concerns of persons with an ostomy may not have changed much through the decades, we are better prepared to address their questions and issues and ensure they live full, productive lives.

References


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