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A Long View of Nascent and Current ET/WOCN Ostomy Care

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INTRODUCTION

This paper is written from the perspective of a first-hand participant and reporter of events intimately known to me because of my own long standing experience as an ileostomate at the tender age of 20 years in 1965 and as an active participant in lay and professional ostomy rehabilitation efforts and organizations since 1970. It is the lived experiences of well adapted ostomates, such as myself, that lends the greatest initial defense to the argument that a sea change in professionally rendered ostomy care needs to take place. There are also the voices of acute care centered ET/WOCNs who express frustration on their professional ostomy discussion forums of the WOCN website at the shortcomings of the acute care environment for failing to meet the fuller needs of their ostomy populace.

Most often when a serious loss of function occurs we apply rehabilitation efforts after the loss. However, when we are planning to prepare a person for a treatment or a procedure that results in loss of normal function we apply prehabilitation efforts beforehand to establish suitability, understanding and acceptance and we begin training that is essential to the whole process of post treatment interventions. In the case of elective ostomy surgery the benefits to the patient are manifestly greater when s/he has been given opportunities to learn about the changing anatomies and functions of the diverted organs, the importance of protecting the peristomal skin, the selection and use of proposed pouch routines and how to reintegrate these planned changes into a return to a normal life.

Functional ostomy success can be summarized by a simple equation that captures the relationship of appliance, skin and stoma to the dynamics of the peristomal skin planes and the choices and uses of recommended pouches. In the mid-1970s and early 1980s I and one of my former students originated and formalized this concept.

Happy Ostomate = ∑ ASS + SPD + PPP

Appliance, **S**kin and **S**toma + **S**tomal **P**lane **D**ynamics + **P**referred **P**ouch **P**rofile are the ingredients, properly integrated and understood, selected and applied for a happy ostomate.

However, for a well-adapted and functioning ostomate to achieve a degree of "happiness" about their altered potty routines one must also address the tremendous psycho-social upheaval occurring when normal potty patterns and expectations are so drastically altered because of significant disease and surgical changes. Processes for integrating serious psychological stresses and social changes centering on altered potty behaviors are not typically within the wheel houses of the surgical arena and the acute care arena, and must be addressed beyond tightly prescribed physical algorithms or action plans. Given the commonplace acute care setting of the majority of WOCN practitioners it becomes even more necessary to try against significant odds to expend all the talents and resources to achieve a state of habilitation. We are being forced to try our best to meet goals and outcomes that on paper may seem achievable, but in fact are fleeting wishes. Just as medicine and nursing have justified the need for rehabilitation centers for so many other types of functional and organ losses so, too, do ostomates need the same effort applied to their rehabilitation. It is regrettable that the shortsightedness of the early ET promoters and practitioners trapped the patient into the wrong model for effective prehabilitation opportunities when they established ET practice as an inpatient endeavor.

THE FATAL FLAW

We, the health community of ostomy care practitioners, **should never have placed ET practice in inpatient settings.** The early surgeons who chose to utilize reasonably well adjusted and competent lay visitors from the ostomy groups to assist them more directly in ostomy patient care should have realized that these ostomates were rehabilitated not because of what happened in hospital but what took place elsewhere and over significant periods of time. Long fought and hard won lessons from experience made these lay ostomy visitors into functioning societal humans again. Surgery and nursing should have capitalized upon these very valuable lessons and changed their acute care locus of care model for the ostomy patient. **The process of fully restoring the ostomy patient was not within the lexicon of training, treatment and surgical attempts at cure as typically found within acute care loci.** Further, those enlightened champions promoting better ostomy care within the hospitals where they worked knew they had to improve the immediate post op care of the new ostomate; however, they did not fully understand the ramifications of their shortsighted planning. Salvaging or better yet preventing immediate post-operative and post discharge complications of peristomal skin and stomas was the goal well within the immediate purview of the attending hospital staff; however, it simply was not enough.

One of the classic examples proffered of acute care ET/WOCN perceived success is when the ET/WOCN reports no leaks from the pouches applied while patient is in hospital. However, as so often occurs once the patient becomes more ambulatory at home, the visiting nurse or the patient or the family member is crying out for help because the bag is leaking. Which window of truth is to be relied upon to assert pouching success? Remember, the inpatient, still reasonably quiescent and immobile, can be a success in the hospital and a total failure upon discharge. Is this Janus model to be de rigueur for ongoing ET/WOCN practice? It certainly makes no sense to have two separate beliefs and experiences occupying the same patient outcomes over such brief time periods.

That these early surgeons and nurses failed to fully leverage the lessons learned from the roles of the well-functioning lay ostomy visitors and organizations is made clearer now that we see many decades later the lingering shortcomings of effective and efficacious ostomy rehabilitation as rendered by the outdated model of acute care focus and placement of WOCN practitioners. Common and repetitive shortcomings still include skin breakdown and pouch leaks in hospital and shortly after discharge.

POTTY TRAINING AND SOCIAL NECESSITY

An infant begins life incontinent and lacking volitional control of bodily fecal and urination functions. Underpinning the success of potty management is the existence of intact gastroenterological and urinary tracts, especially the exquisite neuromuscular interfaces of endpoint muscular control. That our bodies have highly sensitive endpoints of defecation and micturition helps in the training of the child to become aware of early voiding signals indicating the need for controlled or volitional potty release. During periods of soiled clothing or diapers the risk for skin injury increases the longer the liquid effluent contacts the skin, and the greater the degree of physical distress felt by the child. Apart from the physical harm to the skin there are the psycho-social harms to the child as s/he is made to feel embarrassed for inadvertent soiling of self. The attempts to help achieve volitional continence of bodily fluids and stool outputs have been colloquially characterized as potty training, which does not happen in short order but takes many months or longer to achieve success. External soiling of clothing, diapers and such have ceased when the child achieves a state of controlled volitional elimination of bodily waste products. Time, patience and repeated training and reinforcement of acceptable "potty" skills are required to achieve desirable physiological and social outcomes. When this stage in human development occurs the child is welcomed to participate more fully in social interactions and achieves a higher plane of self-control and social acceptance.

Breach the accepted and expected social norms of potty control and risk the wrath of expressed disgust, ridicule and ostracism. Aside from the cries of a child suffering skin soiling are the odor offenses that are becoming additional signals of unpleasant outcomes of incontinence. The ensuing stigma of potty loss is not only a powerful motivator to help keep everyone in line but also a frightening state of being once it is lost. Hence, the origins of severe psychosocial distress felt when one has an ostomy and must now struggle to master anew potty control with a wholly different set of obstacles, equipment, techniques and rituals.

OSTOMY IS AN IDENTITY CRISIS OF IMAGE AND FUNCTION, AND REQUIRES LIFELONG TRADEOFFS

Attempts to re-educate someone who has lost the use of previously established and accepted volitional potty control will require the necessary time and efforts to succeed once again in achieving some new measure of potty control, albeit in a way very different than the prior norm.

When a serious change in ability to maintain volitional functional control of bodily parts occurs the concept and application of persistent rehabilitation efforts have been utilized. Injuries to or loss of limbs, eyes, ears, and post stroke injuries are but a few examples whereby appropriate rehabilitation efforts and requisite prostheses have been utilized to help restore functional capacities. In the process of achieving such rehabilitation efforts it has been made abundantly clear that time and concerted training and reinforcement are critical to permit an adaptation, adjustment and acceptance of the new way of functioning. The loss of volitional control of the endpoints of urine and feces is not unlike the loss of a body part needing rehabilitation efforts to resume functional control. If this statement is held true then it should follow that a requisite rehabilitation protocol should be implemented to permit the ostomy patient to achieve adaptation, adjustment and acceptance of the altered potty routines.

EARLY CONCEPTS OF FOCUSED OSTOMY CARE

Among the earliest examples of rehabilitation efforts was the establishment in 1949 of the Colostomy Ileostomy Rehabilitation Association (CIRA) of the Philadelphia, PA region. In 1965 I became an active member of this group after my permanent ileostomy surgery. The name of this group was deliberately selected to reflect the goals and mission of the lay ostomy members, namely to help in the rehabilitation of people with all types of ostomies. In fact, among the other lay ostomy support groups, not only were some of them targeting only one type of ostomy, none had incorporated the term rehabilitation as part of their group name as had the Philadelphia group. However, all lay ostomy groups were of the same mind and intent when they sought to foster a better rehabilitation outcome. Realizing that these progenitors of targeted ostomy counseling have almost three quarters of a century of established utility should be helpful in shaping the argument for changing the acute care focus of current ostomy management efforts. Throughout the country there emerged numerous local lay ostomy support groups that eventually formed national and international groups. Why did these groups come into existence? Primarily because their needs and goals for full ostomy rehabilitation, adjustment and acceptance were not met while inpatients. To this day ostomy support groups throughout the world remain a vital link in assisting ostomates with adjustment and guidance not available anywhere else. The need for ostomy support groups is still as vital and necessary as when founded seventy-five years ago.

Apart from the lay ostomy counseling groups were the nascent efforts of some surgeons and physicians who wanted to

establish ostomy specialists, whether prior well-adapted ostomy patients or nurses, to monitor their own patients immediately post op and in outpatient clinic settings. Albert Lyons, George Schreiber and colleagues of Mount Sinai Hospital in New York City were one example as were other hospitals throughout the country during the 1950s and 1960s. It was the efforts of Rupert Turnbull and Norma Gill from the Cleveland Clinic to apply the term enterostomal therapist that took root and provided the foundation for a concept of targeted ostomy care within the hospital setting. In Boston during the 1950s to 1960s an effort was taken to assess the longer term rehabilitative needs of permanent ostomates by John Rowbotham and Edith Lenneberg, who later became the first president of the nascent North American Association of Enterostomal Therapists (NAAET).

Prior to the targeted ET role was the role of the lay ostomy association visitor programs that were heavily utilized by most concerned surgeons and medical personnel. The program was arranged so that experienced and well-adjusted ostomates could visit potential or new ostomy patients in order to facilitate acceptance of and adaptation to proposed surgery. Just as Norma Gill had been extensively utilized as an ostomy visitor and troubleshooter by her Cleveland Clinic surgeon, Rupert Turnbull, many others had benefited from a pre and post-op lay ostomate visit and found this interaction life changing and very hopeful. At this time in history **the impact of the ostomy visitor program was among the key reasons for the establishment and success of the lay ostomy organizations, and of the ET concept**. It also became a lifeline for aiding both patients and surgeons. However, when the targeted ET role was being formulated there was initial push back by many hospital players throughout the country. What if there had been a different approach to leveraging the functions of the qualified and fully adjusted lay ostomy visitor? What if these visitors were given the additional training and orientation to hospital protocols and the opportunities to work more closely with the timing of planned ostomy surgeries? In the era of the 1950s to the 1960s the acceptance of ostomy visitors seeing patients at the behest of the surgeons and other physicians was well established and encouraged. At this juncture the more attuned and concerned surgeons truly appreciated the valuable role they served to further the adjustments and rehabilitation goals for their ostomy patients. Ironically, the opportunities to improve upon the role of the lay ostomy visitors was diverted away by a different strategy of selecting a key ostomate to become a specialized technician and later the new entity of a hospital placed enterostomal therapist.

This redirection of function from visitor to hospital-based inpatient employee shifted the sense of ownership in the minds of some early ETs about their role as ostomy therapists. Loyalties to their champion surgeon and institution became a prime consideration for their energies and focus. It did not take too long for some of these early ETs to start to utilize the lay ostomy visitors less, especially since these early ETs were themselves ostomates and could readily fulfil this role as well as their newly found professional role as an ET. It has become a lingering sore point to realize that acute hospital placement of ETs and later WOCNs has seriously interfered with the adoption of a truly rehabilitation mindset and process. No doubt, having surgeons pushing as champions for ET care satisfied their agenda for coverage of their patients in the immediate perioperative cycle and within the very environments in which they operated and rendered follow up care. This arrangement also allowed for direct oversight of the ET function as well as the opportunity, if needed, to run interference for the ET should the ET need it. In the earlier days of developing ET positions in other parts of the USA, resistance was put forth by a number of hospital nursing hierarchies; an experience I wrestled with at several hospitals throughout my geographic domain. The champions employed to overcome these obstacles were usually found among the better attuned physicians and surgeons whose patient populations included fledgling ostomates. Now, it is no longer the case that resistance to utilizing hospital based ET/WOCN specialists remains a serious obstacle; however, the 8 hour day and five day work week persists for many ET/WOCN specialists. This reluctance for changing coverage schedules remains fixed in a time warp and notably problematic as expressed by some current ostomy specialists.

It is important to remind the reader that current hospital stays for many procedures have shortened greatly secondary to advances and innovations in medicine and surgery, along with the drive for economical management of health care expenditures. These external forces have had a significant impact upon how health resources and dollars are being employed, and while at first glance these changes can be viewed as positive outcomes, they do not necessarily address and remedy the shortcomings of truncated time frames and reduced opportunities for effective and necessary ostomy rehabilitation outcomes. It is one thing to address innovative technical success but it remains quite another to find that shortened hospital stays are now worsening the opportunities for early ostomy learning and adjustment, let alone the absence of even the minimal amount of consistent and effective post discharge ostomy follow through.

Can anyone involved in any rehabilitation effort applied to significant bodily changes and functional losses, such as ostomies, claim success in only a matter of days or weeks? Highly unlikely. So, what do those specializing in ostomy care do? They try their best under increasingly difficult settings to manage the ostomy patient. Management of the ostomy patient is the captive term used to explain their role and process.

CHANGES THAT TRULY IMPROVED LIFE WITH AN OSTOMY

It could be argued by different practitioners in ostomy care that their role is significant in alleviating suffering and restoring the patient to a life worth living. If we were to ask the professional reader to explain the contributions made to the ostomy patient we would likely receive a litany of efforts that benefited the patient. What would they be in order of magnitude? If we consider the unique challenges that an ileostomy presents then it may serve as the model for assessing four historical interventions most helpful to the rehabilitation of the ostomate. If we recall the relationship of the stoma to the peristomal skin we could suspect a connection of prime importance. Considering the stoma, what is important here? Not forgetting loss of volitional control and storage capacity, what historical contributions were critical to the beginning of ostomy rehabilitation? The 1930s brought the drainable ostomy

pouch by Strauss and Koenig that finally allowed one to contain and drain at will; the 1940s brought the lay ostomy groups into existence; the everted stoma in the early 1950s mitigated the serious serositis dilemma; the 1960s brought hydrophilic skin barriers, karaya followed by carboxymethylcellulose barriers and pastes, that finally brought an enhanced measure of adhesion and skin protection from digestive enzymes. These four historical turning points led to greater success with ostomy care and rehabilitation, and they remain the cornerstone of ostomy rehabilitation for without them no amount of medical or nursing intervention could advance the well-being of the incontinent ostomy patient.

THE PERISTOMAL SKIN REVEALS THE SHORTCOMINGS

In the world of rehabilitation of a person with an ostomy it has been the case that the ability to return to functional independence is not a short course of effort. It takes time and repeat training in the understanding of causes and remedies for the ostomy and the myriad prosthetic choices to meet the variable needs and changes that a person with an ostomy may and often does present. That so much has been acknowledged about the peristomal skin threats and challenges bedeviling ileostomates and others with liquid outputs should reinforce the concept of rehabilitation needed to prevent and mitigate these persistent risks through prevention strategies and long term evaluation and remediation, a process wholly within the realm and goals of prehabilitation. Among the range of skin breakdowns occurring around ostomy sites, and apart from the idiopathic and systemic disease related ones, the most common type of peristomal skin breakdown relates to the leakage effects of ostomy effluent upon the peristomal skin. This particular failure of maintaining appliance (pouch/wafer) and skin interface is at the heart of the struggle preserving continence for the ostomy patient. Soiling and skin distress of these peristomal zones bring the full weight and despair of incontinence to bear upon the well-being and psyche of the incontinent person. If the peristomal skin is critical to ostomy rehabilitation why is it still reported under regular threat by patients and practitioners? What boat are we missing here?

PARADIGM CHANGE TO CONSIDER

Anytime a suggestion for a paradigm shift or change is made there is usually a body of evidence that warrants it. What is the evidence that now raises the concern for a paradigm change in ET/WOCN practice? What would you consider useful to change about current WOCN ostomy care practices? Could we use the persistent evidence of ongoing peristomal skin injuries as a consideration for warranting a change in our current models of care? How is it that after all these decades we still report regular incidences of skin breakdown. What are the ongoing contributing factors? Why do we still accept them? Why do we not make a concerted to finally stop these skin injuries? What shortcomings from our end as ostomy care specialists may be contributory to persistent peristomal skin breakdowns? If we consider ourselves expert in managing skin why are we not more effectively securing peristomal skin integrity? Clearly, it must not escape any reasonable reader and practitioner involved with ostomy patients that something we are or are not doing remains a failure when we are still subjecting ostomates to persistent skin failures. If we all recognize that an intact peristomal skin surface is essential for ongoing progress in ostomy acceptance and adaptation, then we must focus more strongly on the circumstances that contribute to this recurring failure.

As any well trained ET/WOCN should know, the relationship of the intact peristomal skin to the rest of the ostomy rehabilitation process is immutable. No effective ostomy progress can move forward without at least ensuring good skin integrity. As any good ET/WOCN knows, learning all the steps to ensure peristomal skin integrity does not happen in an instant. One does not read a chapter or two about how to manage a newly created ostomy and then consider success inevitable. Just as an infant and young child gradually learns to master potty control so, too, does the newly created or infant ostomate begin to learn the stepwise progressions to ostomy continence. Without overstating the obvious, it is reasonable to suggest that not enough meaningful time and effective instructions or training are being given to the newly created ostomate. No need to argue in these pages as to why the current state of affairs exist. It is self-evident to any current hospital and post discharge based practitioner. Outside economic and societal forces are also wreaking havoc as efforts are applied to distribute or constrain scarce health-care resources.

INTRODUCING PARETO

What better way to fulfill one's obligations than through direct accountability, without some of the boundaries arbitrarily placed upon practice guidelines by numerous outside players. As long as involved individual parties are agreeable to the terms directly enumerated and fulfilled, then the contract for goods and services is reliable and defensible by current legal and professional standards. Each party in the transaction is made whole without any Pareto imbalance or inefficiency; that is, no one is made worse off by the contract. When one considers the risks of Pareto imbalances between small versus larger entities it becomes more problematic to avoid harms and inefficiencies as the number of competing players or participants increase.

How does the concept of a small and direct contractual arrangement benefit the relationship of an ostomy patient to his or her professional caregiver? Where to begin? When ostomy care was the singular focus of the ET/WOCN there was more time and targeted talent brought to bear for each of the parties. This singular focus of interest and care brought a greater deal of satisfaction and accountability to both parties. Now we need to ask whether or not expanding the roles of the WOCN has not resulted in an imbalance of Pareto optimality for the ostomy patient. When someone gets trained as a WOCN the expectations from other health care team members is for that WOCN to participate in the care of wounds, ostomies, and (in)continence patients. It may be the case that some of these WOCN folks are inclined to limit their interests in a specific type of patient even though their newly created span of roles has created a wider arena of expertise expectation. This narrowing of focus does risk expectation conflicts between the WOCN and the other healthcare providers, as well as the patients expecting appropriate attention. As the WOCN loyalties and abilities became more generalized, again, it became less clear and more confusing as to exactly how expert

they are in any one specific area. By expanding areas of interests under the WOCN umbrella the possible risks of diminished expertise and focus for the ostomy patient is leading to Pareto imbalances with someone being made worse off, be it the patient or other care providers. It is important to reinforce the reality that ostomy care specialists came into existence because the population of physician and nurse generalists had failed to meet the specialty needs for effective ostomy rehabilitation.

An attempt to remedy this shortcoming has been employed by the WOCN Society in the form of specific certifications in either ostomy, wound, continence or foot care subspecialties. What is ironic about this change is that it had been argued by me at an annual IAET meeting in 1983 for a complete separation of ET practice from the nascent push by the IAET society to expand the ET role into wounds and continence management areas. I suggested that the ETs can remain focused on ostomy care and the others within the society could breakaway and create their own entity of skin care providers. I even offered up a recommendation that they call their new group SKIN for society keeping integument normal and that they use the initials IN for integument normalizer. Now, the concept of the WOCN, the wound, ostomy and continence nurse, becomes a bit more muddled since the carving out of discreet interests and roles makes accountability and capacity more confusing. I have noted that less than 20% of the available WOCNs are competently practicing in the ostomy arena. Does this not become problematic for those ostomates who are not getting the full benefit of services by a WOCN for their successful rehabilitation? From observations and writings found within the ostomy discussion forums on the official WOCN members' website the level of ostomy knowledge for some is less than it should be. The levels of frustrations expressed by some old timers and newbies also speaks to the shortcomings of the current teaching and practice models of current WOCN practices for ostomates. If we also add in the changes in hospital time frames and the loss of teaching and practice so critical to ostomy rehabilitation are we not also contributing to a Pareto imbalance? We think one would be hard pressed to answer in the affirmative that the current ostomy population is not getting short changed.

Consider the concept of the 80/20 rule implicit in the Pareto principle which states that 80% of the consequences derive from 20% of the causes. To us the most salient aspect of a Pareto imbalance in the ostomy arena is noted when we fail to ensure the integrity of the peristomal skin. If one were to review the pieces that contribute to the overall success of a rehabilitated ostomate one could list a number of important ingredients in order of priority.

1. The development of an adherent bag or pouch system, especially for those ostomates with liquid effluents. This innovation of the 1930s was the brainchild of the Chicago surgeon Alfred Strauss and his ileostomy patient Henry Koenig. Apart from the very early periods of ostomy appliance innovations and manufacturing, the bulk of the talent, innovation and advances in ostomy pouches arose from within the pool of patient inventors and employees, scientists and research and marketing staff of the manufacturers.
2. Another important step was the lay ostomy organizations who laid the groundwork for the earliest examples of ostomy rehabilitation and the eventual development of the specialized role of the ET. It is likely the case that, but for the lay ostomy visitors, the awareness of ongoing rehabilitation needs and success would have escaped recognition of the early surgeons.
3. The next step was the development in the 1950s of the mucosal eversion of the stoma by Bryan Brooke in England and Crile and Turnbull in the USA. The surgical innovations of proper stomal construction and placement are within the domain of the surgical entities, who may or may not utilize guidance from others assisting in the rehabilitation of the ostomate. To date we do not know of any ET/WOCN who is doing the actual stoma surgery.
4. The development of effective skin barriers, starting with karaya and then the more modern hydrophilic barriers added greatly to the arsenal of ostomy care success. These unique and serendipitous developments and utilization of skin protectants owe their origins to the dental and food additive and stabilizer marketplaces.

Taken together these early developments represent the critical steps in the evolving rehabilitation success of the ostomy patient. If these four important developments represent 100% of the potential for ostomy rehabilitation success then where did we go wrong as current ostomy practitioners failing to assure 100% rehabilitation outcomes? Which of these developments resulted in the Pareto 20% fault cause? We still have effective pouching systems. We still have everted stomas constructed in most if not all ileostomies and urostomies and a great number of colostomies. We still have effective skin barriers and related products. We still have viable lay ostomy organizations. Where is the shortcoming coming from? The answer may lie in the lack of an arena of ostomy potty prehabilitation with teaching, counseling and follow up that needs to be done over an extended time period pre and post operatively and not constrained by shortening hospital stays or by practitioners whose locus of care remains mostly within the acute care setting and who may not be fully leveraging the role of the lay ostomy visitor.

How much longer will the acute care model of ostomy rehabilitation be allowed to continue? How much longer will the WOCN society accept less than satisfactory ostomy rehabilitation outcomes? How much longer will the ostomy client be subject to Pareto imbalances and harm?