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Fire in the Belly and the Professionalization of Nurses: A Historical Analysis of Crohn Disease Care

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Abstract

Today professional nurses around the world are stepping up to meet the needs of individuals with Crohn disease using their specialized knowledge and skills that demonstrate areas of expertise that have not always existed. The gastrointestinal-specific knowledge being used by these 21st century nurses exists today because progressive efforts of nurses in previous decades moved the profession of nursing forward. The purpose of this paper is to describe and analyze the development of the role of nurses in responding to new challenges patients with Crohn disease face since the emergence of the disease in the early 1900s. The authors used traditional historic research methods to conduct the study. Primary sources include nursing journals and textbooks published in the 20th and 21st centuries and documents archived at The Mount Sinai Hospital in New York City, where Burrill B. Crohn conducted his seminal work. The significance of the findings is that the changing role of nurses in caring for patients with Crohn disease mirrors the professionalization of nursing during the 20th and early 21st centuries.

Although I have the support of the organization and physicians with whom I work closely to establish an APN [Advance Practice Nurse] role in the context of IBD [inflammatory bowel disease] care, I must also be certain to articulate an identifiable distinct level of practice that reflects the education, skill, autonomy, and level of decision-making that encompasses the competencies inherent in ANP [advanced nursing practice] (Westin, 2009)

In 2009, Lisa Westin wrote these words as a part of a project she submitted while working toward a master of nursing degree in the Advanced Practice Leadership Program at the University of Victoria, Canada. Today, Westin and other professional nurses around the world are stepping up to meet the needs of individuals with inflammatory bowel disease (IBD) by using specialized knowledge and skills that demonstrate areas of expertise that

have not always existed. The history of nurses' involvement in the care of patients with Crohn disease (CD), one of two common forms of IBD, demonstrates the way in which nurses have professionalized their practice during the 20th and early 21st centuries.

Background

Crohn disease, a condition first described in 1932, became increasingly prevalent in the 20th century and continues to present a variety of puzzling challenges to health care providers. Abdominal pain, diarrhea, and rectal bleeding diminish health-related quality of life for many individuals diagnosed with CD. The annual estimated \$3.6 billion spent on CD care in the United States contributes to the burgeoning cost of health care (Kappelman et al., 2008). Yet, little has been written about the history of nursing care of individuals with this debilitating chronic illness.

The purpose of this paper is to describe and analyze the development of the role of nurses in responding to new challenges faced by patients with CD since its description in the early 1930s. The nurse's role is described within the medical and nursing context of the period. In addition to analyzing the overall role of nurses in caring for patients with CD, this study focuses on the contributions of nurses working at the Mount Sinai Hospital in New York City, where physicians led the world in identifying and pioneering leading-edge CD management and enjoyed widespread recognition for the care of these patients in the decades since (Aufses & Niss, 2002a).

Methods

Traditional historic research methods were used to conduct this study. Several research questions guided the extensive review of the literature. These included: (a) What was the state of the art of medicine and nursing during the period 1945 to 1985, the period when CD incidence rose precipitously (Sandler & Golden, 1986)? (b) How did the body of nursing knowledge about CD change over time? (c) What priorities were evidenced by nurses who wrote about the care of patients with CD? (d) How did the nursing specialties of ostomy therapy and gastroenterology nursing develop? Primary sources used in the study included nursing and medical publications of the period, as well as policy and procedure manuals from the archives of the Mount Sinai Hospital New York.

Bowel Inflammation: Developing a New Focus

Nursing care of individuals with diarrhea and bowel inflammation predates professional nursing. Early generations of Americans who often struggled with diarrhea and bowel inflammation caused by polluted water or infected milk were treated with plants such as pigweed, partridgeberry, and lilac bark (Bauer, 1969). Generally, individuals afflicted with infectious diarrhea recovered or they died.

In the 1900s, chronic, *non-infectious* bowel inflammation became common and proved to be incurable. It was a new type of *fire in the belly*. Although not deadly, the symptoms characterizing the new bowel inflammation were lifelong. Breakthrough drugs, surgeries, and treatments emerged to address acute needs of patients with CD. Nursing knowledge of the care of patients with CD grew as hospital nurses assisted with new gastrointestinal (GI) procedures and cared for debilitated individuals admitted to hospitals for surgical removal of diseased intestinal segments. Nurses participated in administration of total parenteral nutrition to resolve malnutrition in individuals diagnosed with CD for whom repeated surgeries resulted in a new condition labeled *short bowel syndrome*. Nurses of the 20th century helped patients with CD adjust to major life changes in what they could eat and how they would empty their bowels, and they also helped patients adjust to a new self-image.

By the late 1900s, nurses had entered the scientific discussion of CD pathology and had begun designing pertinent clinical research. By engaging in these aspects of care for patients with CD, nurses developed an expanded role for nurses by focusing on problems associated with chronic bowel inflammation. By doing so, these nurses prepared the way for today's advanced practice nurses to manage the care of individuals with CD in the role of advanced practice nurses.

Modernization: What did it Mean for Crohn's Disease?

Societal trends in the United States may have contributed to the rise in the incidence of CD during the 20th century as epidemiologists note greater CD prevalence in populations of affluent individuals who work in white-collar or sedentary jobs, reside in non-rural areas, and habitually consume a refined diet (Bernstein et al., 2001; Burkitt, 1984; Lakatos, 2006; Sandler & Golden, 1986). After World War II, the United States experienced economic expansion that produced more affluence for many Americans (Brenner, 2003). Over time, large industrialized food producers absorbed small one-owner farms, sending farmers and their families away from rural areas toward more urban and suburban employment opportunities (Adams, 1988).

When many Americans migrated to the suburbs, living became more sedentary, with 75% of American families owning automobiles and a "standard mix of durable household gadgets" (Rostow, 1959, p. 12). Industrialization of foods in the presence of better roads put highly refined convenience foods into the hands of more Americans (Schwartz, 1976). Refined foods such as Wonder® bread, frozen TV dinners, and Twinkies were on the market by the 1940s, and in the 1950s, such convenience foods gained widespread popularity (Hostess Cake, 2011; Library of Congress, 2010; www.wonderbread.com/wonder-bread-history.html). A cluster of environmental characteristics associated with CD marked the second half of the 20th century. That is, Americans became increasingly affluent, adopted more sedentary lifestyles, and depended on more refined convenience food than they had in the past.

The Rise of Science

Meanwhile, scientific advancements in the second half of the 20th century produced an environment in which individuals experiencing this new chronic *fire in the belly* could survive, receive treatment, and their disease activity could be monitored. Antibiotics, discovered in the late 1920s, clinically tested in the late 1930s, and experimentally used with success in World War II, proved to be important weapons in the battle against postoperative infection and increased the success rate for abdominal surgeries (Hirsh & Doherty, 1952; Van Epps, 2006).

Advances in pharmacology produced an additional array of non-surgical treatment options that specifically benefited patients with CD. Sulfasalazine, originally synthesized in the late 1930s and used for rheumatoid arthritis, became the most prescribed drug for long-term treatment of mild to moderate CD (Peppercorn, 1985). Parenteral antibiotics became an important part of the therapeutic regimen for patients with CD accompanied by an abdominal mass or fever (Peppercorn, 1985).

By 1961, Lomotil was useful as a nonspecific antidiarrheal drug and over time began to be used cautiously in patients with mild to moderate CD symptoms (Kasich, 1961; Peppercorn, 1985). Advances in endocrinology resulted in the first synthesis of cortisone in 1946 (Hillier, 2007). By 1985, corticosteroid therapy was a mainstay of treatment for CD (Peppercorn, 1985). Azathioprine, originally developed for organ transplantation, contributed new adjunctive drug therapy for the management of CD by 1985 (Peppercorn,

1985; Toledo-Pereyra, 2005). Development of these new drug therapies represented some of the most important aspects of the medical management of CD between 1945 and 1985 (Peppercorn, 1985).

In addition to pharmacology, advances were made in blood typing, anticoagulation, blood banking, and fluid and electrolyte management. These improvements decreased the risks associated with abdominal surgery in the second half of the 20th century (Aufses & Niss, 2002b). Acceptance of Wilhelm Rontgen's x-rays as an adjunct to medical diagnosis expanded during the first decades of the 1900s (Howell, 1996). A PubMed search on keyword 'barium enema' yields articles demonstrating that by the late 1940s, barium enemas were commonly used, thereby adding visual contrast to x-ray images. This improvement in x-ray technology aided physicians in making more precise diagnosis and evaluation of the extent of bowel inflammation without the patient undergoing surgery.

Eventually, colonoscopy further enhanced the management of CD, although the colon's length and tortuous turns prevented colonoscope development until fiberoptics advancements in the 1950s made it possible to transmit an image via the scope (Haubrich, 1987). Colonoscopy design enhancements in the 1960s produced a clinically useful application of colonoscopy that was presented in 1967 to a gathering of the American Society for Gastrointestinal Endoscopy (ASGE) (Haubrich, 1987). The flexibility of the colonoscope, its steerable distal end, and clear image launched a new era in the 1970s, marked by widespread use of colonoscopy-enhanced management of CD and other intestinal diseases (Hunt, 1983).

Finally, the rise of specialization in health care influenced the response of nurses who were charged with delivering care to individuals with diseases of the gastrointestinal (GI) tract. Whereas little specialization existed in 19th century health care, by 1945 physicians were working within many well-defined medical and surgical subspecialties, including gastroenterology (Aufses & Niss, 2002a). Nursing, too, had begun to divide into specialties, including pediatric, obstetric, geriatric, public health, and psychiatric nursing (DeLora & Moses, 1969). In the presence of a growing body of gastroenterological knowledge, nurses gained experience with patients diagnosed with gastrointestinal problems and self-organized into additional new specialties such as ostomy nursing and gastroenterology nursing.

Naming the New Disease

Physicians at Mount Sinai Hospital New York captured the attention of gastroenterologists nationwide in the early 1930s. A total of 14 patients with localized hypertrophic ulcerative stenosis of the terminal ileum provided the basis for Dr. Burrill B. Crohn's description of the new disease entity that he presented to the 83rd annual meeting of the American Medical Association in New Orleans, Louisiana, on May 23, 1932 (Birch, 1973). Leon Ginzburg (surgeon) and Gordon Oppenheimer (pathologist) had collected and systematically categorized excised inflammatory intestinal masses from many individuals and were responsible for identifying 12 of the 14 cases highlighted by Dr. Crohn at the convention (Baron, 2000). Thus, all three physicians' names appeared on the pivotal publication (Crohn, Ginzberg, & Oppenheimer, 1932). The name *Crohn's disease* appeared sporadically for decades, and use of the eponym had solidified by 1977 when British surgeon Bryan Brooke published his book titled *Crohn's Disease: Aetiology, Clinical Manifestations and Management* (Brooke, Cave, Gurry, & King, 1977). It is unclear whether Crohn's name became identified with the disease because he alone presented it to the powerful American Medical Association, or because his name was listed first on the seminal publication, or because he out-proselytized the others on behalf of the new disease.

Nursing Silence: 1932 to 1955

From the time of its initial description, CD was addressed in medical literature and was referred to as *regional ileitis* or *regional enteritis*. In contrast, an investigation of nursing literature uncovered no information regarding CD during the same period of time (Rothweiler & White, 1947; Wolf, 1947). Nurses may not have viewed patients with CD as a group because cases were few and widely dispersed. Specialty areas had not yet developed and patients were grouped as medical or surgical, not according to specific diseases. Perhaps the unpredictable course of CD and heterogeneity of the presenting symptoms reduced the nurses' ability to see CD patients in aggregate.

After World War II, many nurses left the profession to stay at home; moreover, the efficiency of hospital wards was sacrificed to provide the privacy of individual hospital rooms, which were created within the renovations fueled by the 1946 Hospital Survey and Construction Act (Keeling, 2007). These changes added to the strain of keeping up with rising demand for hospital nursing care. Typically, nurses did not include analysis of observations they recorded in their nurses' notes (Keeling, 2007). Nurses who cared for patients with CD in the middle of the century may have been awaiting physician-developed education and solutions to problems associated with the new disease entity. It may be that all the above factors combined to jointly silence the nursing literature on the subject of CD from 1945 to 1955.

At the same time, nurses had begun to care for individuals with ulcerative colitis (UC), and this experience helped prepare them to meet some of the overlapping needs of individuals with CD. UC is a similar, non-infectious inflammatory bowel disease that was recognized earlier than CD (Hutchinson, 1905). *Ileostomy*, with removal of the entire colon, was found to be a curative surgical procedure for UC because damage related to UC occurs only in the colon. Ileostomists, individuals who were suddenly faced with fecal diversion to an abdominal stoma, began meeting together to discuss mutual challenges to daily living. In 1952, Albert S. Lyons described early meetings of the QT Alumni Club, a group that first met in private homes and then began meeting at Mount Sinai Hospital New York (A. S. Lyons, 1952). Lyons credited Mount Sinai nurse and social worker Lucy Neary with promoting the group, and he further reported that other nurses attended the meetings, learning from patients as the patients "considered and solved" (p. 812) the problems of an ileostomy, discussing "the best bags, paste, cleansing methods, and deodorants" (p. 812).

As Lyons described the group meetings, nurses at Mount Sinai who visited the QT Alumni Club meetings probably witnessed the reassurance new members experienced when they interacted with fellow members who had already regained normalcy while living with an ileostomy. Furthermore, nurses probably rejoiced along with the group when members married and when "the first pregnancy was followed eagerly by the entire group" (p. 812). Indeed, Lyons reported that the QT Alumni Club educated "the entire hospital personnel (doctors, nurses, social workers) in the best methods of managing the ileostomy" (p. 812).

Nurses React to a New Procedure: 1955 to 1965

Between 1955 and 1965, nursing journals, including *RN*, *American Journal of Nursing*, and *Nursing World*, published articles about ileostomy without mentioning it as a possible surgical outcome for patients with CD (Dericks, 1961; Evarista, 1956; Scott, 1960; Seide, 1960). Seide (1960) reported that 95% of ileostomies were performed because of UC without mentioning any other cause.

Nurses wrote about ileostomy care within a holistic framework. In addition to presenting detailed procedural steps and pictures of relevant ileostomy equipment and appliances, nurse

authors addressed important emotional needs of ileostomy patients. Throughout nursing articles, responsibility for ileostomy care rested squarely upon the nurse, while acknowledging that nurses' best sources of information continued to be the lay ostomy clubs.

Scott (1960) wrote an article titled "The Nurse and the Ileostomist" suggesting that ileostomies would "soon become as common as the now familiar colostomy" (p. 29). Yet many nurses had not had the opportunity to become familiar with ileostomies. She explained two differences between an ileostomy and a colostomy: (a) enzyme-laden ileostomy drainage is able to digest protein and therefore breaks down skin surrounding the stoma; and (b) ileostomy drainage is liquid and therefore remains less controllable than the more solidified and intermittently passed colostomy drainage. She also underscored the ongoing lack of expertise among nurses by citing the findings of a survey of 54 ileostomists, 70% of whom were cared for by nurses who "knew nothing about the specific requirements for taking care of an ileostomy patient" (p. 29). Her solution, typical of others, was to promote the work of ostomy clubs for both nurses and patients. Indeed, Scott made it clear that postoperative care was within the realm of nursing, not medicine, explaining that the surgeon's focus was the "development of the surgical technique" (p. 29).

Nurse Elizabeth Katona, who organized a remarkable and sustained effort to improve ostomy care, opened her presentation to the 1964 American Nurses Association convention by describing the impetus for her ostomy work:

I observed that one patient, Mr. L., was visibly disturbed when the doctor told him he was to be discharged .... later I returned to the patient to see what his problem was and how I might help him with it. He demonstrated his problem by opening his robe and exposing his abdomen which was covered with bulky dressings stained with fecal drainage. Mr. L looked at me helplessly and asked, "How can I go home with this?" (Katona, 1964, p. 19).

By 1967, Katona had implemented a nurse-run weekly clinic format to care for hundreds of ostomy patients and their families over a 7-year period (Katona, 1967). The extensive knowledge presented in her publications is evidence of a transition that was occurring in the area of ostomy care. Patient-led ostomy expertise was already giving way to nurse-led ostomy expertise, although the professionalization of ostomy care within the domain of nursing would be a gradual process that would take place over a number of years (WOCN, 2011).

Nurses Continue to React: 1965 to 1975

Between 1965 and 1975, nursing journals published *surgeon-authored* articles about CD, while nurses still wrote about ileostomy without mention of CD (Andersen, 1970a; Andersen, 1970b; Edwards, 1970; Watt, 1973; Williams, 1971). Nevertheless, there is evidence that nursing knowledge of CD was advancing rapidly. To understand the progression of events that led to development of the new knowledge base, it is important to examine the rise of the specialty of gastroenterology nursing.

The advent of specialized operating rooms and intensive care units in the 1960s allowed nurses to develop expertise in specific areas, much the same as physicians did. As doctors learned to use the new technology already described, nurses learned new ways to assist the doctors in performing new procedures made possible by the emerging technology. Today's Society of Gastroenterology Nurses and Associates (SGNA) has recorded its history online and traces its roots to the work of nurse Marna Schirmer, who as early as 1969 worked in the endoscopy operating room at Mount Sinai Hospital New York (SGNA, 2011). Driven to

improve the assistance nurses could provide during GI procedures, Schirmer attended annual meetings of the ASGE alongside physicians in 1970 and 1971. At these meetings, she networked with physicians to compile a nationwide list of nurses who assisted with gastroenterology procedures so that these nurses could exchange procedure-related information. By 1972, a core group of nurses had assembled a steering committee and a mailing list of 300 nurses. In 1973, for the first time, nurses gathered in person to discuss gastroenterology issues. Thus, from the efforts of one visionary nurse, the roots of a sustainable nursing specialty organization began to grow.

Formation of the new GI nursing specialty was accompanied by the appearance of new gastroenterology nursing textbooks. The Given and Simmons textbook (1975) provided eight pages of comprehensive *nurse-authored* CD information not found in nursing journals between 1965 and 1975. These eight pages of CD information included pathophysiology, clinical manifestations, diagnostic measures, treatment, nursing care, and parenteral hyperalimentation. Nurse-authored information regarding CD was not found elsewhere in nursing literature between 1965 and 1975.

Increased Specialization and Certification, 1980s

By the 1980s, nurse-authored information about CD appeared in many publications, including nursing journals. For example, *Crohn disease* became a major heading in the Cumulative Index to Nursing and Allied Health Literature, encompassing multiple subheadings. Nurse Carol Butler wrote “Supporting the Patient with Crohn’s Disease” and nurse Doreen Lyons wrote “Crohn’s Disease” (Butler, 1983; D. Lyons, 1984). *The Lippincott Manual of Nursing Practice* outlined four pages of CD information (Brunner & Suddarth, 1978). The 1984 edition of Given and Simmons’ *Gastroenterology in Clinical Nursing* textbook increased their coverage of CD from eight pages to 35 pages (Given & Simmons, 1984). *The Nursing Clinics of North America* published a lengthy symposium on inflammatory bowel disease with 68 pages of comprehensive CD information organized into six articles (Hagenah, Harrigan, & Campbell, 1984; Lewicki & Leeson, 1984; Simmons, 1984; Sparacino, 1984; Stotts, Fitzgerald, & Williams, 1984; Wilson, 1984). Nurses had begun to address the subject of CD.

Although non-nurse enterostomal therapists were grandfathered into the specialty of ostomy care and some surgeons continued to stay involved in ostomy care issues, professional ostomy care had clearly come to rest within the domain of nursing by the 1980s. The history of enterostomal therapy is currently posted on the Wound, Ostomy and Continence Nurses Society Web site (WOCN, 2011). History reveals that as the decade of the 1980s began, admission slots within enterostomal schools were already reserved for RNs only, and the American Nurses Association had already begun to play a key role in decisions related to enterostomal therapy certification (WOCN, 2011). In addition to these signs of advancing specialization among ostomy nurses, a new and highly specialized periodical was created, the *Journal of Enterostomal Therapy*. Through this specialty journal, ostomy nurses were able to communicate with one another at a higher level than was possible in journals written for non-ostomy nurses (Goode, 1983).

Policies and procedures at Mount Sinai Hospital New York also reflected an increasingly complex knowledge and skill base of nurses related to CD and ostomy care in the 1980s. For example, there were six specific ostomy guidelines written to cover the wide variety of products being used for ostomy care at the time. Additionally, written policy in 1984 specified that only registered and practical nurses were to “participate in the prevention, patient education and treatment of skin excoriation around stoma site(s)” and further, “all

ostomy patients should be referred to the Ostomy Nurse clinicians for consultation. Ext. 7231" (Weissman, 1984, No. 62F, p. 1).

Adaptation to imposed change remained a constant characteristic of nurses' response to caring for patients with CD in the 1980s. Safe delivery of drugs and monitoring of side effects became more complex as new CD drugs emerged (Keeling, 2007; Peppercorn, 1985). Patients underwent ileostomy surgery and nurses were expected to assume the role of enterostomal therapist, providing physical and emotional rehabilitation to assist patients' successful adjustment to the role of ileostomist (Smith, 1985). Total parenteral nutrition became a practical solution for meeting the extreme nutritional needs of patients with CD, and nurses were expected to learn to administer the new therapy and monitor its effects (Given & Simmons, 1979).

Surgeons developed a continent ileostomy, by creating an internal pouch, and nurses learned to establish fecal continence for their patients through catheterization and drainage of the pouch (Hyman, Ashenmacher, Williams, Pelchar, & Tucciarone, 1977). Manufacturers invented a stoma cap and magnetic ring aimed at preventing leakage, and nurses learned to help patients build their tolerance to the device (Given & Simmons, 1984).

Additionally, nurses in the 1980s evidenced greater self-determination and professionalism. Published nursing research emerged, testifying to nurses' interest and initiative to lead in areas of concern to patients with CD. Nurses began asking innovative questions and designing research studies to answer their questions. For example, in 1983, nurses published results of studies titled "Sexual Concerns in the Patient with an Ileostomy," and "Media Coverage of Ulcerative Colitis and Crohn's Disease" (Kristy & Pichert, 1983; Rolstad, Wilson, & Rothenberger, 1983). The same year, Debra Broad, President of the International Association for Enterostomal Therapy, published an introspective look at the enterostomal specialty and described how specialization without inter-specialty communication and support can lead to fragmented care (Broadwell, 1983). Furthermore, Part V of "an eight-part series documenting the present and the future of enterostomal therapy" (p. 169) analyzed results from a questionnaire completed by nursing administrators and surgeons (IAET, 1983). Enterostomal nurses of the 1980s clearly sought to evaluate their professional nursing care and their specialty through the eyes of those with whom they shared a mission.

Conclusion

The early nursing response to the emergence of CD was shaped by historical expectations that nurses would follow physician orders and implement guidelines established by the medical community. Yet, the nursing response was reshaped over time as nurses closed gaps in care, developed specialized areas of expertise, and organized into self-regulating specialty associations. Nurses have entered scientific discussions about CD and related issues by asking research questions and designing studies to investigate these questions. In 1982, Mount Sinai surgeon Albert Lyons challenged physicians to continue the search for innovations for CD (Lyons, 1983). As this search for innovative care continues, it is important to note that nurses have now fully joined the scientific table.

The chronic and incurable nature of IBD heightens the need for specialized health care and ongoing research. Nurses equipped with specialized knowledge and skills related to CD can help stretch limited resources to meet rising health care demands in the current health care climate. Nurses practicing in IBD-related advanced practice roles are increasingly filling the gap (Belling, Woods, & McLaren, 2008). Such was not always the case. However, thanks to progressive efforts of past nursing leaders and increasing interdisciplinary collaboration, nurses who have a holistic perspective and science-driven orientation are positioned to do

more than simply react to immediate needs associated with CD. Advanced practice registered nurses such as Lisa Westin are at the forefront of health care system reform by creating new roles that previously did not exist to improve health outcomes for patients with IBD. This type of transformation is not easy. It requires a different kind of fire in the belly, the kind of fire that nurses have demonstrated in the past.

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