Nursing Research and Continen

t Care

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“Let us each and all realizing the importance of our influence on others — stand shoulder to shoulder — and not alone, in good cause.” Florence Nightingale

Nursing care of the person with urinary incontinence has had a long and, at times, difficult history of insensitive treatment, nursing burden, and treatment based on opinions and tradition rather than solid research. This article is a tribute to the nursing leaders who led the way for the continence researchers of the 1990s. The seminal research activities and publications of Thelma Wells, Molly (Mickey) Dougherty, Joyce Colling, Pat Burns, Jean Wyman, and Joanne McDowell have been critical to the current state of the science of continence care.

Florence Nightingale was the first to clearly articulate that cleanliness and order were paramount in all aspects of patient care, including elimination. Chamber pots “without a lid should be utterly abolished;” “Don’t make your sick room into a sewer.” But a lack of understanding of both the etiology and treatment of incontinence meant that care could only be respectful and directed towards comfort, points which were emphasized in two key nursing textbooks: A Textbook of Nursing (Weeks, 1891) and Nursing: Its Principles and Practice (Hampton, 1893). Not until the 1950s would nursing begin to influence care by conducting research in the area. A textbook of note is Bertha Harmer and Virginia Henderson’s Principles and Practice of Nursing substantially revised 5th edition published in 1955. Several pages were dedicated to incontinence, skin care, management with a catheter, condom drainage, penile clamp, and incontinent pads, and the comprehensive reference list includes most of the research to that date. The authors emphasized that incontinent patients deserved respect and that the problem was amenable to therapy. “A hopeless attitude toward incontinence in the aged is inconsistent with high standards of medical and nursing care” (p. 461).

World War II saw women and nurses participating on equal footing with men. Women moved out of the kitchen and onto the shop floor as welders, riveters, and mechanics. “Rosie the Riveter” of WWII gave way to a more independent woman of the 1950s. Meanwhile, sulfonyl amides and antibiotics revolutionized the care of the urologic patient. Moreover, veterans and polio patients who survived spinal cord injuries required rehabilitation. Specialized units opened; nurses became involved in the urologic and bowel sequelae of spinal cord injury and the overwhelming psychological impact of incontinence. Incontinence topics appeared regularly in gynecology and urology journals and appeared for the first time in

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1953 in the index of the *American Journal of Nursing*.

**Early Nursing Research**

Nursing research in continence and urology was focused on cost savings of procedures or types of equipment: transurethral resection versus open prostatectomy (Perry, 1934), metal versus red rubber catheters for intermittent catheterization (Parisa, 1936), or mineral oil versus glycerine for the lubrication of red rubber catheters (Aquadro & Barbour, 1938). In the 1950s, conservative management gained favor. Two landmark papers by Dr. Arnold Kegel proposed that stress urinary incontinence could be treated nonsurgically by exercising pelvic floor muscles. Other physician-directed studies evaluated electrical stimulation for treating stress urinary incontinence while drug studies evaluated alpha adrenergics (ephedrine and transeptin).

At the same time, a most important event for nursing was the American Nurses Association’s (ANA) announcement in 1952 to devise new ways of improving nursing service based on research. In 1955 the American Nurses Foundation (ANA, 2002) was established to conduct research, provide research grants, and publish scientific papers.

Dr. John Brocklehurst in Manchester, England, a contemporary of Kegel, became a vocal advocate for the elderly. Indeed Brocklehurst’s *Incontinence in Old People* (1951) changed attitudes. A fore runner in the field we know as geriatrics, Brocklehurst was a true leader in the study of “old people.” He wrote that unless the etiology of incontinence was understood, little progress could be made in ameliorating the problem. He helped design beds for the intractably incontinent and debilitated and was one of the first to identify precipitating factors of incontinence: cerebral vascular accident, becoming bedfast, and increased mental confusion. He implemented an innovative activity regimen in the facility; at the beginning of the program all patients were bedridden, a year later, 25% were “on their feet” during part of the day, greatly improving the morale of the patients and giving them independence and control.

**Divulging a Secret Problem**

The role of nursing in incontinence care as we now know it began in the 1960s: Thelma Wells graduated with her diploma in 1962 and degree in 1968. Prior to her master’s degree, Thelma volunteered at a nursing home and met “Sophia,” a Russian immigrant seamstress whom Thelma befriended (Wells, 1999). Sophia eventually confessed to Thelma that she had a “secret” (urinary incontinence). Thelma could not accept the lack of available treatment for incontinence. A man had just landed on the moon; surely incontinence was a treatable problem. A visit to the library confirmed that the information on incontinence treatment was sparse or absent — a finding that Jean Wyman made in 1980 when she was in a similar situation.

In the United Kingdom in the 1960s, the problem of incontinence was the most overtly severe because of the large numbers of elderly housed in outdated Victorian structures. A courageous book, written by Barbara Robb (1967), a nurse who was deeply concerned about the plight of the elderly, described the conditions of the nursing facilities. The report occasioned several governmental inquiries on the care of the institutionalized elderly between 1960 and 1972. A notable master’s thesis in social science at the University of Edinburgh was also completed by Esther Ann Reid in 1974: *Incontinence and Nursing Practice: An Investigation of the Nursing Management of Soiling in Non-Bedfast Patients*. At the time, no information existed on the impact of incontinence on nursing care. Reid reviewed nursing practice. Incontinence was identified as a huge problem which was unpleasant for the staff and patients alike. It was into this type of setting that Thelma Wells pursued her PhD under the guidance of Professor John Brocklehurst, in Manchester.

Nursing research on urinary incontinence (and many topics) gradually appeared in the literature in the 1960s and 1970s. During this decade seven studies were published on incontinence with five of the seven focusing on some sort of behavioral management of incontinence. Although the designs were flawed, Thelma Wells (1994) points out that these studies were the first in their class to provide a nursing care focus to what had been largely considered (and still was) an unpleasant nursing problem. In addition to research and publications, professional organizations such as the American Urological Association Allied, the Association for Continence Advice in the UK, and the International Continence Society lent credibility to the study of incontinence and provided a structured forum at which nurses could meet and discuss the issues.

The etiology of incontinence remained misunderstood: “Urgency,” wrote Frewen in 1972, “was one of the most frequent psychosomatic disorders in gynecology and represented nearly one third of all cases of urinary incontinence.” Frewen was one of many who recommended Valium® or Librium® in conjunction with bladder retraining and anticholinergics for urge incontinence. Despite an incorrect conceptualization of the etiology of urge incontinence, the treatment with bladder retraining and urge suppression is still current today. These methods were represented in a more systematic way in 1991 by Jean Wyman and Andy Fantl, and now form part of the recommended treatments of any expert continence nurse.

**Research Advances**

Federal involvement meant that major advances in continence care occurred in the 1980s. The National Institute for Aging called specifically for incontinence studies. Nursing leaders
Pat Burns, Joyce Colling, and Jean Wyman were all successful in receiving grants in this area. Such a landmark achievement by nurses was unprecedented in the medically dominated research world and set the standard on which all other applications continue to be based. The National Institute for Nursing Research (NINR) also sought studies on urinary incontinence. On a practical level, disposable products finally made it into the marketplace, replacing such ineffective measures as rolled up newspapers or other homemade remedies. Yet incontinence remained a taboo topic: the magazine, Modern Maturity, would not print incontinence information; the television news show Prime Time would not cover any issue related to bladder control. Recruiting subjects for research studies was a challenge in itself because no one would talk about the problem, especially not the sufferers.

In the 1980s, despite a growing awareness of incontinence, the problem in geriatrics remained unaddressed. Thoughtful and important published work by Thelma Wells started to percolate new ideas with respect to elderly care but progress was slow. After finishing her PhD and attending research meetings, colleagues chided Wells for her interest in “old ladies with wet pants.” She found a kindred spirit in Dr. Frank Williams in 1980, the second director of the National Institute on Aging, who helped turn around the research on urinary incontinence. Dr. Williams’ interest was in function and he solicited funded studies that explored dysfunction. For Thelma Wells this was a great stimulus for exploring the etiology of incontinence; Dr. Williams was always willing to listen, was ready for change, and was collaborative in his thinking. In 1982 Wells was the first nurse to be principal investigator on a National Institutes of Health (NIH) funded grant to study urinary incontinence. Wells and Carole Brink formed a lasting and productive relationship and they became one of the first teams to operate a nurse-run incontinence clinic. Between them, Brink and Wells opened many doors; one as a researcher and the other as a nurse practitioner. Together they published articles, wrote book chapters on geriatric incontinence, and worked on standardizing measures to assess pelvic floor strength (others were also working on this, notably Mickey Dougherty).

In 1981, Molly (Mickey) Dougherty presented a paper on physical activity in menopause as part of the work she was doing with a gynecologist who wanted to bring menopause and the climacteric to the world. Dougherty was using a slide from Nettor’s famous series on the pelvic floor and as she was speaking she wondered, “how do these exercises help to control continence?” and “how does one measure the effect of the muscle contractions?” To answer these questions, a significant linking occurred with Physiologist Dr. Bob Adams. Between them, Dougherty and Adams mobilized the research on intravaginal devices and were precedent setting for measuring pelvic muscle function. For Dougherty, this early work lead to a lifelong program of research in circumvaginal muscle strength.

Dougherty’s first major grant was in 1984, entitled “Circumvaginal muscle activity.” Because of the attitudes of the time, the term “vaginal” was not acceptable to those advertising the grant and Dougherty was asked by the grant administrators to change the title to “Managing lower urinary tract dysfunctions in aging women.” During this time, Jean Wyman and Dougherty shared ideas and Dougherty credited Wyman with sharing and collaborating, leading to further studies on intravaginal balloon devices. Similarly, Wyman gives credit to Dougherty for stimulating her interest in technology and her encouragement and support in attaining major research funding; Wyman also salutes the support and mentorship she received from Thelma Wells. Dougherty’s final study in Florida was a community-based project testing the efficacy of conservative therapies in older, rural women with urinary incontinence.

Behavioral and Psychological Aspects

In 1983, a liaison was formed between Jean Wyman and Andy Fantl that would set the standard for behavioral aspects of continence care. At Virginia Commonwealth University the research team pushed continence care forward by their influential research on bladder retraining and on measuring the impact of incontinence: The Incontinence Impact Questionnaire (IIQ) and the Urogenital Distress Inventory (UDI) for Women. The IIQ was the first instrument to capture the psychological aspects of urinary incontinence in women. Many quality of life and impact questionnaires have followed but the IIQ continues to be one of the most widely used and has been recently validated for men, making it even more versatile.

In 1983, the National Institute of Aging and National Institute of Nursing Research put out a call for clinical trials in urinary incontinence. Thirteen proposals were submitted resulting in five awards; Pat Burns was the only nurse to receive a grant. Her success was a major coup for nursing research and gave nursing a huge “kick start” in the field of research in urinary incontinence. Her work has focused mainly on incontinence in women, and the role of the nurse practitioner in particular. Burns’ major study, a randomized controlled trial of pelvic floor muscle exercises or biofeedback, provided an important foundation for further work in the field. Burns and Joyce Colling have both developed their own patented products.

Joyce Colling’s dissertation focused on choice and control over activities of daily living (ADL) by patients in nursing homes. One hundred and thirteen patients in 15 nursing homes were interviewed to determine
what control they believed they had over their ADL. Participants were asked questions about eating, dressing, sleep, social activities, and toileting. By far the most problematic was toileting: distressing to residents because staff did not come to toilet them when they called them and distressing to staff because they often did not understand the residents’ need to void often or at night.

This led to her first major grant, $1.3 million, using Robert Wood Johnson Teaching Nursing Home grant sites to determine if a form of habit training could decrease the frequency and volume of incontinence among these frail elderly persons. The results showed that an individualized toileting program did decrease incontinence; however, staff perceived this to be more time consuming and did not continue the toileting process, which gradually allowed UI rates to return to baseline.

More Research Strides

In 1985, the National Institute of Nursing Research became a reality and the following year Colling and her team were successful in receiving a multisite continuation of the initial work and take it forward into the homebound population and foster care facilities. The team found similar findings in foster care as found in nursing homes. In the homebound population, paid caregivers had less understanding and seemed less likely to toilet their clients than caregivers in the nursing home study. Elderly family members, caring for a spouse or relative were motivated to provide toileting assistance and expressed gratitude to research staff for teaching them better toileting techniques despite their own health problems and the burden of caregiving responsibilities. Thus, while regular toileting significantly decreased incontinent episodes and volumes among the 78 persons completing the 6-month intervention period, family caregivers sometimes chose to manage incontinence with absorbent products when caregiving burdens became too great. An offshoot of the work by Colling was Taylor Harden’s study on urinary incontinence in black women. Of note was that Colling identified what others had believed — that without ongoing support and commitment by staff and management, continence programs were destined to fail. These findings were confirmed recently by Brenda Roe in a review of implementation of clinical practice guidelines.

Among the NINR provisions, the law authorized the creation of the National Center for Nursing Research (NCNR) at NIH, with acting Director Dr. Doris Merritt and then Director Ada Sue Hinshaw. The impetus for establishing NINR came from the findings of two federal studies: a 1983 report from the Institute of Medicine recommending that nursing research be included in the mainstream of biomedical and behavioral sciences, and a 1984 NIH Task Force study identifying nursing research activities relevant to the NIH mission.

Joanne McDowell’s career began when Dr. Kathy Burgio came to Pittsburgh for a 4-year appointment in 1987. Dr. Burgio was a senior staff fellow in the Gerontology Research Center, National Institute on Aging from 1981 to 1987 and assistant professor, medical psychology in psychiatry/behavioral sciences at Johns Hopkins (1985-1989). These appointments were her first career steps in continence therapy. At the University of Pittsburgh, she brought her ideas grounded in psychology principles and applied them to biofeedback treatment for urinary incontinence. Her early students were McDowell, Diane Smith, and Diane Newman. McDowell’s skill with biofeedback was then carried into the clinical area in the Benedum Geriatric Center at the University of Pittsburgh. The research funding also allowed a clinic: 5 days a week; the group advertised in the newspaper for women 60 or over who were experiencing urine leakage. There were so many calls, a new line had to be installed. A major finding in the study was that even subjects who completed only a bladder diary improved up to 40%, showing the possible benefits of heightened awareness of voiding and fluid intake patterns.

The work expanded in 1992 when Dr. Sandra Engberg and Joanne McDowell received a NINR grant to study treatment of incontinence in the homebound elderly, a study which was a fine example of research using clinical practice strategies of the real world rather than trying to isolate one particular method. Unknown to Mickey Dougherty at the time, she was instrumental in having the Engberg and McDowell study go forth. Dougherty and her colleagues had just published a paper comparing surface EMG electrodes to vaginal or rectal probes, reporting that they were equally reliable. These findings provided the necessary supportive research to effectively implement their own study in the home; their subjects would have been reluctant to have invasive biofeedback (to say nothing of the awkwardness of inserting a probe in a subject whose mattress was soft and bed sagging). In addition to Mickey’s work on EMG and the support of Sandra Engberg, McDowell credits Joyce Colling with sharing many helpful ideas on homebound patients.

The past decade has been one of turbulence and lurching forward far faster than could be imagined in the previous 5 decades. Mikel Gray completed his PhD in 1990 and raised the bar at nursing conferences as he challenged nurses to study and understand the physiology of voiding and urodynamics. In 1992, Mary Palmer was proactive in advocating health promotion when management of symptoms was the primary focus of continence care. Gray and Palmer, among others, became the new wave of continence advocates. Most importantly, health care reform became a reality.

The Agency for Health Care Policy and Research (AHCPR) (now the Agency for Healthcare
Research and Quality) convened a consensus development conference in 1992 to “improve reporting, diagnosis, and treatment of UI; reduce variations in clinical practice; educate health professionals and consumers about this condition; and finally to encourage further biomedical clinical and cost research on UI.” Kathleen McCormick and Ananias Diokno chaired this landmark conference which summarized the research to that date through the publication of clinical practice guidelines (AHCPR, 1992). Dr. McCormick was nursing research director at NIH, National Institute on Aging, during the time the guideline was written. Of particular importance was the condensed handbook for health care professionals as well as the pamphlet for the consumer.

Despite the progress being made, there was still no specialty group representing nurses concerned with urinary incontinence; Jean Wyman was key in having nursing respond to the proposed guidelines by “rattling a few cages” at the ANA. The ANA, acting because of Wyman’s persistence, called groups together, surveyed specialist groups, and invited major nurse researchers to meet at the 2nd National Multi-Specialty Conference on Urinary Continence in 1994 to discuss, among other topics, “the role of nurses (and disciplines such as physiotherapy and occupational therapy) in the care of the patient with urinary incontinence.” In 1996, a second edition of the AHCPR guidelines was printed, informed by advances in care but also identifying areas still neglected. The mandate was unchanged. Now archived, this particular document has informed health care professionals and decision makers nationally and internationally (AHCPR, 1996).

**Where Are We Headed?**

Despite 50 years of attention to continence care and pivotal nursing research in the field, incontinence continues to challenge health care professionals and consumers alike. In a 1997 Angus Reid survey by the Canadian Continence Foundation, 12% of those surveyed over 55 years of age stated they experienced incontinence often enough to be a problem, yet many were influenced by myths that “urine leakage is normal at my age” or “nothing can be done about it.” Of the people with incontinence only half had consulted a physician about the problem. Why is this? Although 50% of primary care physicians in Ontario see at least one patient a week with incontinence, 29% never ask about incontinence, and 85% underestimate the prevalence of incontinence in females (Schultz, Klag, & Drutz, 2000). Sixty-two percent of recent graduates from family practice feel that their education and subsequent understanding of urinary incontinence is inadequate; in nursing, the Victorian Order of Nurses identified a lack of knowledge, low priority, lack of support, and inadequate resources as barriers to effective nursing care of people with incontinence.

There is power in collaboration and it is the collaboration that will maintain the momentum of continence care and push clinicians and researchers forward. The most recent example is, of course, the Continence Coalition of the Society of Urologic Nurses and Associates and the Wound, Ostomy, Continence Nurses Society who worked unceasingly and with absolute commitment to voice the concerns of patients and to stand firm in the face of government resistance to fund biofeedback. Their cause was united and supported by nursing research — the very research conducted by the continence “pioneers.”

The next decade will be one of solidifying what we know and applying these findings to routine rather than only specialized practice. We will continue to challenge and explore current approaches to care — many are not based on strong evidence — but more importantly, we will ensure that effective continence care is available to all.

**References**


**Additional Reading**