Norma N Gill: a symphony of resilience and reform in Enterostomal Therapy

ABSTRACT

In the midst of Akron, Ohio's industrial prowess and profound social unrest, Norma N Gill emerged not merely as a pivotal figure in Enterostomal Therapy (ET) but as a beacon of hope and innovation amidst personal and societal struggles. This narrative seeks to weave the threads of Gill's life, her personal battles with health, and her unwavering faith, into the broader tapestry of a society grappling with racial inequality and social injustice. While her professional collaboration with Dr Rupert Turnbull has been celebrated in medical annals, it is the intersection of her work with the societal dynamics of her era that this exploration seeks to illuminate. By delving deeper into Gill's life and work, we aim to shed light on how her personal experiences and societal context merged into her ground breaking contributions to medicine and stomal therapy, thereby offering a nuanced understanding of her enduring impact.

Keywords Norma, Gill, Enterostomal Therapy, history, stomal therapy

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INTRODUCTION: THE HARMONISATION OF PERSONAL STRUGGLE AND SOCIETAL CHANGE

Norma N Gill, often heralded for her transformative work in stomal therapy,¹⁻⁵ lived a life that was a symphony of personal struggle, societal change, and professional innovation. Her story, while deeply embedded in the medical advancements she pioneered, is also a narrative of how personal and societal challenges can forge a path of resilience and reform. Set against the backdrop of Akron, a city that was a crucible of industrial innovation⁶⁻⁸ and deep-seated racial and social issues,^{9,10} Gill's journey from personal health crises to becoming the 'Mother of Stomal Therapy¹¹' is not just a medical tale but a social and human one. This exploration seeks to intertwine the threads of Gill's personal and professional life, providing a richer, more nuanced understanding of her contributions to Enterostomal therapy and medicine within the context of the societal challenges of her time."

AKRON'S IMPRINT ON NORMA GILL'S JOURNEY

Akron, Ohio, during the 1950s, was a city where the brilliance of industrial innovation and the shadows of social unrest coexisted. Renowned for its significant contributions

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However, beneath the surface of industrial success, Akron was also a cauldron of deep-seated social and racial tensions. 9,10 African Americans, many of whom had migrated north seeking enhanced opportunities, encountered a stark reality of marginalisation and systemic discrimination. They were subjected to significantly lower wages compared to their white counterparts 10,15 and were stripped of basic human dignities. 15



Norma N Gill



The USS Akron flying over its namesake city, ca 1931-1933, via Ohio Memory



An Akron sign

Akron, simultaneously a stronghold for the Ku Klux Klan, was a reflection of the deeply embedded racial prejudices of the era. 16,17

This racial tension was not isolated but part of a larger, nationwide issue stemming from the historical roots of the slave trade. Even after the abolition of slavery in the 19th century, its legacy continued to permeate the United States, giving rise to the 'Negro Question' – a discourse aimed at addressing the systemic inequalities faced by African Americans. Intellectuals, including John Stuart Mill and Albert Einstein, contributed to this discourse, with Einstein poignantly stating in a 1946 New York Times Magazine article: "It is easier to denature plutonium than to denature the evil spirit of man".

In the neighbouring state of Indiana, Jim Jones manipulated the desperation for racial equality, culminating in the tragic deaths of over 900 individuals.²⁰ This event underscored the complexities and perils of racial and social issues, illustrating how the pursuit of equality could spiral into catastrophe.

Born in Akron in the 1920s, Norma N Gill was not a mere observer of these societal complexities. At 18, she married Edward 'Ted' Gill, a supervisor at the General Tire rubber factory, and seemed destined for a life centred around her community. However, her faith, deeply influenced by her Baptist grandmother, who also had a colostomy, became a pivotal force in her life. Norma's faith was not merely doctrinal;

it was experiential, marked by profound spiritual insights and visions, highlighting her sensitivity to the human spirit.²¹

Norma Gill navigated through significant personal challenges that further sculpted her life and career. After the passing of her first husband, Edward 'Ted' Gill, in 1974, she found love again, marrying Herbert G Thompson in 1983, whom she met at a class reunion. This new chapter in her personal life coincided with her unwavering commitment to her professional and community endeavours.²¹

Norma was actively engaged in discussions around the 'Negro Question'. The racial disparities and social tensions she witnessed were not merely intellectual debates; they were tangible, daily issues in her community. This emotional tension within Norma inspired her to envision a sanctuary where African Americans could practice their faith, free from the racial prejudices of her era. Norma aspired to establish a church where people of all races could find faith, offering a compassionate and ground breaking response to the racial biases that afflicted her community and her time. ²¹

THE UNVEILING OF SUFFERING: NORMA GILL'S BATTLE WITH ILLNESS

In May of 1948, Norma Gill's life trajectory took an unexpected and harrowing turn. She was diagnosed with ulcerative colitis, a chronic, inflammatory bowel disease that wreaks havoc on the innermost lining of the colon and rectum. The diagnosis cast a long shadow over her future, introducing her to a new reality where her daily life was punctuated by 15 to 20 urgent trips to the bathroom, disrupting her ability to care for her family and manage household duties.²¹

The medical solutions of the time presented their own challenges. Cortisone and ACTH, the prescribed medications, were newcomers to the market, and doctors grappled with determining the correct dosage.²¹ The financial burden was also significant: Gill needed six tablets daily, which cost \$37.80 per week or \$1,965 annually. In 1950, when the average family income was \$3,300, this medication alone devoured nearly two-thirds of her family's earnings, compelling her to mortgage her home and seek assistance from her community.^{21,23}

Despite the medications, Gill's health spiralled downwards. Profuse bleeding from her colon ulcers left her in a state of perpetual weakness. At one point, she required a blood transfusion of more than twice her normal blood volume. Her hands blistered and swelled, adding another layer of difficulty to her responsibilities as a mother. Amidst this health crisis, she discovered she was pregnant with her third child. Despite the challenges, something deep within her spirit told her that this pregnancy had a purpose, and she chose to continue it.²¹

FROM DESPERATION TO A GLIMMER OF HOPE

After giving birth, Gill's condition deteriorated dramatically. Nights were particularly challenging; she often had to crawl on her hands and knees to care for her baby, as her husband

worked nights and her mother couldn't stay over. Her 11-yearold daughter took on significant responsibilities, including preparing the baby's formula and giving her a bath.

Soon after, Gill was afflicted with Pyoderma Gangrenosum (PG), a rare and painful autoinflammatory disease characterised by large, necrotic skin ulcers.²⁴ The ulcers were debilitating, appearing on her legs, face, trunk, and abdomen. On her face, they were so severe that she later required plastic surgery. On her legs, the ulcers were so agonising that flesh would fall off the bone, exposing nerves and emitting a horrible smell of decaying tissue. The pain was so intense that she resorted to wrapping her legs in towels overnight to collect the fluid oozing from the ulcers. However, the mornings brought even more agony: removing the towels caused her such pain that tears would stream down her face.²¹

In the midst of this torment, she turned to God for help. Seeing the future looked so bleak as she really felt she was dying, she made a vow that if she did survive, she would dedicate her life to serving others. Life was very difficult: she lived one day at a time.²¹

Through meditation, she found a way to distance her mind from the relentless pain. She later realised that what she was practicing was Transcendental Meditation (TM). TM involves the repetition of a mantra in a specific manner, allowing the mind to settle into a state of deep rest and relaxation. This technique has been shown to reduce cerebral blood flow to painful stimuli by 40-50%, thereby providing relief.²⁵

A PIVOTAL MOMENT: CRISIS AND TRANSFORMATION IN NORMA GILL'S JOURNEY

In December 1953, eighteen months after the birth of her daughter, Norma Gill encountered a crisis that would become a turning point in her life. Emergency services, struggling to detect her pulse and observing her skin turning a cyanotic shade, rushed her to her local hospital. Doctors worked through the night, stabilising her condition, and after four intense days, she was sent home for Christmas. However, her ordeal was far from over. Gill, sensing the fragility of her time, sought spiritual guidance through prayer. In 1954, perplexed doctors in Akron referred her to Cleveland Hospital.



Upon arrival, the medical team was confronted with a shocking sight: Gill's body was so swollen she couldn't wear shoes, and she exhibited an enlarged liver, iritis, and bone issues. After four weeks of intensive care, she began to stabilise and was introduced to colorectal surgeon Dr Rupert Turnbull. Despite her abdomen being enveloped in ulcers, scar tissue, and scabs, Turnbull identified a suitable spot for an ileostomy. Gill found a touch of humour in this, as she genuinely couldn't identify a clear patch of skin for the stoma. Nevertheless, the surgery was successfully performed.²¹

PATHWAY TO HEALING: NAVIGATING THE ROAD TO RECOVERY

Post-operation, Gill embarked on the path to healing, albeit with complications along the way. Dr Turnbull was particularly concerned that Gill's weakened physical state and prolonged use of cortisone would compromise the sutures, making them unlikely to hold. To aid her recovery, Gill was advised to consume a protein-rich diet, especially since parenteral nutrition was not available at the time. Despite initial healing, Gill faced another challenge: her abdomen was so laden with scar tissue and ulcers that her surgical appliances would not adhere, leading to leakage issues. The solution was a Dempsey Mattress with a hole, allowing her to lie face down so her ileostomy effluent could drain into a pan, aiding the healing of her abdominal skin. She remained in this position for two weeks, sitting up only to eat.²¹

A NEW CHAPTER UNFOLDS

After enduring nine weeks in Cleveland Hospital and navigating through additional surgeries, including the removal of her rectum and the repair of a surgical hernia, Gill found herself on the pathway to recovery. Her vitality gradually rekindled, sparking a fresh perspective on life. While the specifics of her future endeavours were unclear, one element was unmistakable: a deep-seated desire to aid others blazed within her. How she would extend this help was yet to be determined; she left that decision in the hands of the 'manupstairs.'²¹



Picture of Pyoderma Gangrenosum to give some idea of the incredible state Gill would have been in

TURNING PAIN INTO PURPOSE: NORMA GILL'S REVITALISED MISSION

Embarking on a volunteer journey at a local city hospital, where she initially distributed mail, Norma Gill began to rebuild her life with a newfound purpose. A referral from her dermatologist opened doors to local surgeons, and soon, her reputation for assisting patients in their struggles, much like her own, began to spread. Gill found herself aiding 28 Akron physicians, providing not only a service but also a beacon of hope to those navigating the complexities of post-surgery life.

In 1958, during a visit to her gastroenterologist, she was encouraged to reconnect with Dr Turnbull. When queried about her activities, she responded with a light-hearted jest that she was venturing into 'his line of work.' This reconnection not only marked a significant step in her professional journey but also symbolised a personal triumph over the adversities she had faced. Gill was not merely surviving; she was thriving, turning her pain into a catalyst for change and support for others navigating similar paths.²¹

THE ADVENT OF MODERN ENTEROSTOMAL THERAPY

By the age of 38, a decade after her initial diagnosis of ulcerative colitis, Norma Gill was invited to join Dr Turnbull as his dedicated Ostomy technician. Their collaboration was more akin to a partnership, with regular consultations on complex cases and stoma management challenges. They approached each obstacle with the determination of detectives piecing together a puzzle.²⁶ Together, they liaised with manufacturers to enhance ostomy equipment and embarked on a mission to educate the broader medical community about this burgeoning field. Their combined vision was transformative, emphasising that ostomy surgery should be viewed as a gateway to an enhanced quality of life, rather than a life marked by despair, isolation, and stigma.²⁷

FROM COMMUNITY EFFORTS TO FORMALISED TRAINING

In the early stages, ostomate support was primarily driven by the community, often taking the form of self-help groups. These informal gatherings, where patients exchanged advice and coping strategies, gradually evolved into the United Ostomy Association and later the International Ostomy Association. Recognising the growing demand for specialised training, Gill and Turnbull took the initiative to establish a school for Enterostomal Therapists in 1961. Due to the overwhelming interest, initial admissions prioritised those with personal or familial experience with stomas, a criterion that remained in place until 1972.²⁸

SPREADING THE MISSION: THE ESTABLISHMENT OF GLOBAL PROFESSIONAL BODIES

Norma Gill's pioneering work didn't go unnoticed and began to captivate surgeons across the globe, leading to the replication of her services and the establishment of similar educational institutions in various locations, such as Grand Rapids,

Michigan, and Harrisburg, Pennsylvania. The necessity for a professional entity became evident, culminating in the creation of the American Association of Enterostomal Therapists in 1968 during the United Ostomy Association conference in Phoenix, Arizona.²¹ This organisation would undergo several evolutions, eventually becoming the International Association for Enterostomal Therapy and later giving rise to what is now known as WOCN (Wound Ostomy Continence Nurses).²⁹

AN ENDURING IMPACT: NORMA GILL'S LEGACY

Norma Gill's tangible impact is not only visible in the institutionalisation and global spread of the field of ET nursing but also in the next generation of practitioners, exemplified by her daughter Sally, who also embraced a career as a ET nurse. A decade after her initial contributions and the formation of the United Ostomy Association, the Department of Colon and Rectal Surgery at the Cleveland Clinic employed eight full-time Enterostomal Therapists, highlighting the growing recognition of this specialised field.³⁰ Today, the profession boasts a global presence, with formal training programs and professional associations dedicated to stomal therapy, ensuring that Gill's influence and dedication to improving patient care live on.

CONCLUSION

'The Unyielding Spirit of Norma N Gill: A Legacy of Resilience and Change'

Norma N Gill, a beacon of perseverance and innovation, leaves behind a legacy that seamlessly blends medical breakthroughs, personal tenacity, and societal transformation. Her odyssey from battling ulcerative colitis and pyoderma gangrenosum to spearheading significant strides in Enterostomal therapy, narrates a story that extends beyond the confines of medical history, permeating the human and societal dimensions of her time. Gill not only revolutionised ostomy care but also epitomised a belief that ostomy surgery should pave the way to an enhanced quality of life, a belief forged from her own tribulations and the societal hurdles she encountered. Her life and endeavours stand as a poignant reminder that amidst the throes of personal and societal adversities, an individual can indeed forge a pathway of hope, innovation, and lasting impact.

CONFLICT OF INTEREST

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