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UNCOVERING FREEDOM: A STORY OF EMPOWERMENT

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ABSTRACT

This article tells the story of a woman suffering from food anxiety and unintentional weight loss and how shifting to an empowerment-based model of care led her onto a path of health and healing.

KEYWORDS: Empowerment, Integrative medicine, Food anxiety

"She's sleeping," cried Angelica, as she tried to explain to her 3-year old daughter why her older sister lay motionless after the car accident. But the three year old Talia could not understand. She gripped her mother's hand as EMS workers rescued them from the wreck. That night Angelica sustained wounds of her mind and body, wounds that would last for decades to come. Thirty years after the accident Angelica came to my clinic for the first time.

She was referred to me by my wife, the pharmacy manager where Angelica picked up her prescriptions. Apparently she had been looking for a new primary care doctor who practiced complementary and integrative medicine and knowing that I am passionate about that approach to health and healing, my wife gave her my clinic's contact information.

Angelica presented with her now 33 year old daughter Talia to discuss what she felt was persistent acid reflux with symptoms including epigastric pain and an occasional acidic taste in her mouth. She stated this discomfort started a few months prior after a particularly severe episode of abdominal pain when eating several grapefruits in a row. Though that initial pain resolved, these minor symptoms persisted. She had tried to eliminate various foods from her diet, but was unable to identify a particular trigger. Acid suppressant medications actually worsened her abdominal pain and caused an uncomfortable throat swelling. Hoping for some non-pharmacological interventions to treat her symptoms, she listened as I told her about the interplay of regular exercise, dietary modifications, and stress management with relation to reflux disease. The plan at the end of the visit was for Angelica to create a detailed meal diary for two weeks to track related symptoms, to begin yoga classes at a local studio, and to practice a therapeutic breathing exercise. Excited about this strategy I had developed for her, she agreed to have a follow up visit in clinic in two weeks.

When Angelica returned to see me, she was much more agitated than she had been on our first meeting. Not only was she continuing to have “gurgling” in her throat, but she also was experiencing dry cough, hoarseness, bouts of anxiety/panic, concerns about weight loss since she has been limiting her dietary intake, and an “intense fear of eating anything”. She was so concerned that she was asking for me to admit her to the hospital so she could get some sort of hydration/nutrition intravenously. The tension, distress, and helplessness she expressed permeated the clinic room.

Reflecting back on this moment, there were four parts to Angelica’s story that were important for me to gather - a story that I gradually weaved together over the course of 3-4 office visits. First, I listened to make sure I understood what her primary concerns were about her health. She mentioned repeatedly that she was worried about having a food allergy or food intolerance, but felt most anxious about having lost more than 11kg in 4 months. Second, the purely medical concerns, in particular her unintentional weight loss, set off some red flags in my mind. Initially her presentation struck me as likely related to an underlying anxiety; however, I was concerned about gastrointestinal disease, food allergies and possibly cancer. Third, the recent history leading up to her current state of health was important to understand the setting for this relatively new set of symptoms. She insinuated that she was under a lot of stress from some construction that was going on around her home, which she found made it difficult for her to eat any food without getting an upset stomach.

Lastly, we discussed the “long story” - a part of her history that occurred 30 years ago and has never ceased to influence her day to day experience of life. This was the car accident that took the life of her older daughter. The accident that also took the life of her husband, who was driving, leaving Angelica and Talia as the only two survivors from the wreckage. Incidentally, after this accident Angelica required emergent abdominal surgeries involving a splenectomy and partial colectomy. She relayed to me that she distinctly

remembers the abdominal pain during these procedures as she drifted in and out of consciousness. Perhaps this pain was related to her current presentation in my clinic?

Having gathered these stories we proceeded with a care plan that involved lab tests and imaging to workup her weight loss, discussions with her allergist to rule out food allergies and mind/body therapies including therapeutic breathing, relaxation exercises, and meditation. We both did research on food elimination diets, often used to identify particular foods or food groups to which a person may be intolerant, and then experimenting with adding foods back that do not produce unwanted signs/symptoms. Unfortunately Angelica was not keen on seeing a psychologist at the beginning of our time together as she had had a negative personal relationship with one many years ago, which ended up leading to a year during which she suffered from anorexia.

I continued seeing Angelica every two weeks for the next six months. Despite frequent visits, deepening of our relationship and an evolving approach to her health and well-being, she seemed to make only modest improvements in the main health outcome that I was concerned about - her weight. As we worked with the elimination diet, she ended up restricting herself more and more rather than pursuing the "challenge" phase in which she would add back foods that her body could tolerate. Her weight hovered around 40kg and although her medical workup for significant etiologies of unintentional weight loss like cancer was reassuring, I felt frustrated. Why didn't the approach we were taking work? She wanted an "integrative medicine" solution to her health, and yet something was missing.

About four months after our first meeting, I attended a conference entitled Integrative Medicine for the Underserved (IM4US), where I first heard the term "empowerment" in relationship to the medical field. The word arose during a presentation about so-called "empowerment group visits", which refers to a group medical visit model in which the focus/discussion of each visit arises from concerns, questions, and challenges in medical care that the *participants* have, rather than from pre-selected topics that the physicians facilitating the groups choose. One key point I learned during this conference was just that - the physician is a facilitator. He or she does not "empower" the participants to live healthier lives or manage their diabetes better. That "power" is discovered by each individual, within his or her own self.

Interested in learning more about this term empowerment, I started doing some research and discovered that this model of care originates from the education literature of Paulo Friere, Brazilian educator and philosopher, and author of *Pedagogy of the Oppressed*. The theme from Mr. Friere's work centered around the importance of education as a "practice of freedom" rather than a means to conform to the "logic of the present system".[1] From this foundational work, health education researchers including Marc Zimmerman and Robert Anderson from the University of Michigan brought this philosophy in the medical setting. They found that by shifting the psychology of patient care to an empowerment model, not only would there be improved health outcomes, but also greater patient investment and understanding of their own health.[2]

When applied to medicine, empowerment is best described as an *approach* to patient care: "Empowerment may be defined as a complex experience of personal change. It is guided by the principle of self-determination and may be facilitated by health-care providers if they adopt a patient-centered approach of care which acknowledges the patients' experience, priorities and fears. In order to be empowering for the patient, therapeutic education activities need to be based on self-reflection, experimentation, and negotiation so as to allow for the appropriation of medical knowledge and the reinforcement of psychosocial skills."[3]

At first I had a difficult time envisioning how this empowerment model would look in practice. Traditionally, a patient would come to my clinic, present a particular problem, and then I would offer solutions based on evidence-supported medical science and clinical experience. In circumstances such as an acute bacterial pneumonia, perhaps this conventional approach is still the most appropriate practice. However, as I learned more about using an empowerment approach to patient care, I wondered if Angelica would derive more benefit from a self-guided treatment plan rather than the directive - albeit "integrative" - approach we were using now.

Over the course of our next few visits together, I mindfully employed this new model of care. First of all, rather than continuing to propose solutions like breathing techniques or elimination diets at her concerns, I brought a pause to our discussions before offering solutions. Limitless mind-body techniques exist that could potentially help her food anxiety, but rather than giving her one after another as I had been doing, I listened. I listened to specifically what fears she had around food and what I heard in the pauses was fear about gaining too much weight, fear of food-induced pain, fear of not eating "healthy" enough. Secondly I noticed how much my previous approach to her care had been very much fear-based, stemming from concern that she was losing weight, unable to take care of herself, helpless, weak and in need of saving. Especially having this patient referred to me by my wife, I felt an obligation, a pressure to be that savior, that protector that I perceived she was seeking. In shifting my attention from what was going wrong with her to facilitating her discovery of her own health, our relationship changed. And our discussions changed. We became less bogged down in searching for external treatments for her weight loss and food intolerance. We started with acknowledging the fear and trauma that was present in her life and building health from the foundation that she already had in many aspects of her life - her relationship with her daughter, her supportive church friends and strong faith life, the volunteer work she participated in and the step-by-step re-expansion of her diet.

To support her own empowerment, she expressed a desire to see a nutritionist and a psychologist who could assist with anxiety related to food, so I helped connect her with people in the community who could facilitate a greater understanding about these aspects of her health. She also acknowledged her increased body weakness/muscle atrophy and a desire to become more physically active, so I ordered a referral to physical therapy to begin this rehabilitation. Over time, rather than meeting every 2 weeks, we started

having clinic visits only once every 1-2 months. And now, as of the time that this article is being written, Angelica has gained back about 5 kg, has continued to discover more and more foods that she can tolerate, and is slowly beginning to strengthen her body.

My skeptic mind asks, "Is this all just a change in rhetoric? How can I prove that using an empowerment approach to care really makes a difference in health outcomes?" Upon reading related health care literature, I discovered that the World Health Organization acknowledged the benefits and evidence base supporting an empowerment model of care in a 2006 report[4] and there are multiple examples of outcome scales used to measure its effect in fields including diabetes, cancer, mental health and rheumatologic disease.[5] As for my N-of-1 experience with Angelica, I found this approach significantly changed my outlook in the clinic setting. I began "letting go" of the illusion of control over my patients' health as well as my belief that "I know what is best" for my patients. With practice I have been able to acknowledge my inherent predilection to a fear-based approach to patient care and ultimately develop a more open, trusting relationship with my patients. Synthesizing my experience and research, I define empowerment as an approach to care that allows for the evolution of sustainable and resilient health on a personal, family or community level. Not only does it leave the patient feeling liberated, but empowerment also brings "freedom" to the clinician. ■

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