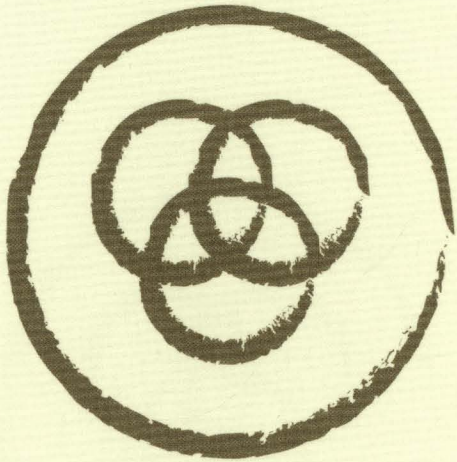
BELIEFS AND ILLNESS

A Model for Healing



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Beliefs and Illness

A Model for Healing

by

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Due to the sensitive nature of some of the clinical narratives and exemplars within Beliefs and Illness, some names may have been changed to protect the identities of those involved.

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To Dr. Chintana Wacharasin, dear friend and colleague, who brought forth and introduced me to her beliefs about families, illness, and living life (all contextualized within her Buddhist beliefs) in a way that caught my attention and admiration.

Lorraine M. Wright

To my mother, Violet Luchak Melenchuk, who showed by example how to live fully an unexpected life alongside illness with creativity, courage, and compassion for others, and whose enormous influence for good continues to live on in my life and in the life of my family in countless ways.

Janice M. Bell

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ILLNESS BELIEFS MODEL
A MAP FOR HEALING

We believe:

Beliefs are the heart of healing. Constraining beliefs increase illness suffering and facilitating beliefs decrease illness suffering.

Illness suffering can be physical, emotional, relational, and/or spiritual. Likewise, healing in individuals and families can be physical, emotional, relational, spiritual, and/or all four.

Softening suffering is the heart, the center, and the essence of caring in our relationships with individuals and families in health care. One of the most useful ways to soften suffering is to invite more facilitating beliefs.

Illness is a family affair. Everyone in a family experiences the illness; no one family member "has" cancer, depression, chronic pain, or renal failure. From the onset of symptoms, through diagnosis and treatment, other family members are impacted by and reciprocally influence the illness.

Serious illness invites a wake-up call about life, which usually leads one into the spiritual domain as the meaning of life is queried or reviewed.

There is a distinction between disease and illness and between medical narratives and illness narratives. We believe illness narratives include stories of sickness and suffering as well as stories of survival and strength that need to be told.

Cellular and "soulular" changes occur through conversations. Our network of conversations and our relationships can contribute to illness or wellness.

A clinician's worldview can open or close opportunities for family members to diminish their illness suffering. We believe a worldview that facilitates healing is one that acknowledges another person as a legitimate other, even though one may not embrace or agree with the other's beliefs. This also implies that the clinician is willing to challenge his or her own beliefs.

One key to therapeutic change is a respectful, curious, and compassionate relationship between a clinician and family members that facilitates discussion of even the most difficult topics and invites the consideration of alternative or modified beliefs.

Therapeutic change is enabled when the core constraining belief—the belief at the heart of illness suffering—is distinguished and challenged.

Changes in beliefs involve changes in the bio-psychosocial-spiritual structures of both family members and clinicians. The direction and pace of change cannot be predicted.

Therapeutic change involves invitations to reflection by family members and the clinician.

Distinguishing therapeutic change sustains and maintains change by strengthening facilitating beliefs.

The privilege of participating in therapeutic conversations about individuals/families' illness experiences provides opportunities for learning and possibilities for changing the biology of the clinician.

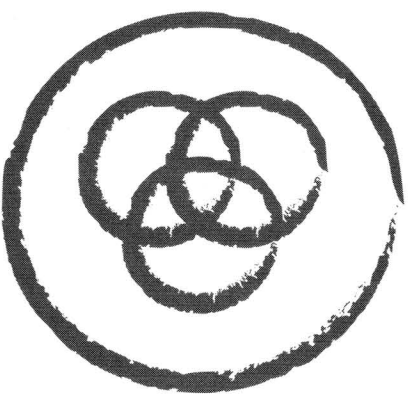
The more a clinician is able to embrace a reality of objectivity-in-parentheses, the more he or she becomes a particular kind of person who brings forth healing conversations in a context of compassion and love.

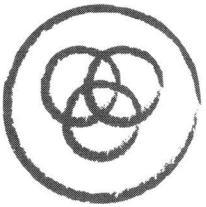
"It is hard to let old beliefs go. They are familiar. We are comfortable with them and have spent years building systems and developing habits that depend on them. Like a man who has worn eyeglasses so long that he forgets he has them on, we forget that the world looks to us the way it does because we have become used to seeing it that way through a particular set of lenses."

—Kenichi Ohmae

PART I

BELIEFS: THE HEART OF THE MATTER





CHAPTER ONE
From Illness Suffering to a Clinical Practice Model for Healing

"The world breaks everyone and afterward
many are strong at the broken places."
—Ernest Hemingway, *A Farewell to Arms*

When Linda and George, a married couple in their early fifties, first arrived at our outpatient clinic, the Family Nursing Unit, University of Calgary, there was obviously something broken between them. Remnants of their last argument, one of the first in their six-year marriage, intermingled with uncomfortable tension and strain—as though one wrong word could send them reeling. Yet, under all that, glimpses of the humor and strong bond between them could still be seen.

At 53, Linda was facing multiple chronic illnesses: diabetes, high blood pressure, fibromyalgia, obesity, depression, and PTSD (Post-Traumatic Stress Disorder) from early childhood trauma. Her most troubling and limiting illness symptoms at the time were pain and fatigue. She could no longer work outside the home and had begun seeing herself as a burden to her husband, on almost every level.

George, a 50-year-old patient care attendant at a local nursing home, was coping as well as he could, but the stress and strain on his marriage was taking its toll. The couple denied any explicit perception of their

experience as "suffering" and saw it only as a part of life. They had labeled Linda's health issues "The Monster," making it a third party in their home. The Monster was swiftly taking over their lives and negatively influencing their marriage, which had always been a primary source of comfort and support.

During a series of seven sessions, George revealed to the clinician, Dr. Janice Bell, that the couple was "used to discussing most everything. She shut me out, so everything seemed to go to the side. There was no communication."

Prior to their work with our clinical team, Linda had fallen into a pattern of keeping her feelings from George, in order to protect him, or so she thought.

"It seemed all we had to talk about anymore was my health, and we started to snip and snap at each other," Linda wrote in a letter to the clinical team after finishing at the Family Nursing Unit.

"I was in a constant state of worry and anxiety," George chimed in. "The tension was so thick. It was making me increasingly unhappy, and so was Linda. I wanted so much to be able to ease her pain, make her feel better, and [make her] interested in what we used to enjoy together. So much of our focus was Linda's health we were unable to find our joy in each other."

Within the first few sessions, the couple showed remarkable ability and resourcefulness to take up the clinical team's suggestions. They even created their own experiment called the NIFT Day—No Illness-or Fatigue-Talk Day (2006). This break in their routine of dealing with Linda's illness symptoms was just what they needed—dedicated time to simply enjoy each other's company again. The day could be spent at an outing, if Linda was strong enough, or on their couch cuddled up with a bowl of popcorn. The activity didn't matter, just that for a dedicated period of time, they had only each other: no chronic illness, no talk of pain and medications, just moments of levity and connection.

This intervention focused on challenging the family's belief that they were powerless to exert any influence over Linda's illness symptoms. We believed NIFT Day would encourage them to begin experimenting with a belief that they had more influence over the illness than they imagined; that they could influence illness symptoms and reclaim their relationship

from "The Monster" of illness.

George and Linda's story of how illness impacted their couple-relationship, and how they joined together to influence the illness, underscores the reality that illness, disability, and death are universal human experiences. The question for individuals and families is not "Will I or my loved ones be spared these experiences?" but rather "When, which illness, how serious will it be, and for how long?" (Rolland, 2003). As families respond to the emotional and practical demands of illness and deal with major changes within the family unit, their needs are often overlooked and unattended by the health care system, with unfortunate immediate and long-term consequences. Clinical practice models are needed that address illness suffering and attend to healing, not just with individual family members, but also at the level of the family unit.

In these pages, we'll explain our clinical practice model, the *Illness Beliefs Model*, for addressing the suffering of families as they experience the challenges of serious illness. The focus is uniquely on *illness beliefs* and the connection between beliefs, suffering, and healing. Rich in clinical exemplars, *Beliefs and Illness: A Model for Healing* takes the reader inside the therapeutic conversation between the health care provider and family members to show the model in action. We'll first describe the systemic, relational nature of the model and then highlight the research and clinical practice that has shaped the model's development.

Illness Suffering is a Relational Phenomenon

Nurses and other health care providers are altering and/or modifying their usual patterns of clinical practice as they shift from caring for only the "individual patient" to seeing the "family as the patient" and increasingly including families in health care (Schober & Affara, 2001; Wright & Leahey, 1990, 2009). To realize that illness is a family affair, and thus focus on the family as the unit of care, requires a conceptual shift, even a paradigm shift, by health care providers. They must now consider a number of factors: the interaction and reciprocity between illness suffering and family functioning, the interaction between themselves and the families in their care, and the larger systems within which families and health care providers exist. A vogue term for this increasing ability of the health care provider to think systemically, recursively, and interactionally

is relational practice (Doane & Varcoe, 2005; Robinson, 1996; Silverstein, Bass, Tuttle, Knudson-Martin, & Huenergardt, 2006; Tapp, 2000; Wright & Leahey, 2009). Involving families in a systemic, relational way in health care is called many different names within the literature, depending on the context of the practice and the health care provider: family-focused practice, family centered practice, family health and healing, family nursing, Family Systems Nursing, systemic health care, family medicine, family psychology, medical family therapy, medical social work, etc.

Beliefs and Illness: A Model for Healing is written for clinicians from a variety of disciplines: nursing, medicine, social work, psychology, rehabilitation studies, occupational health, medical family therapy, and others. Because illness suffering is a relational phenomenon (Marshall, 2007), health care providers in all of these disciplines require advanced practice knowledge and skills to assess and intervene at the level of illness suffering within and across multiple systems levels in order to "soften" illness suffering in individuals and families (Wright, 2005, 2007, 2008). We are grateful to Marga Thome, University of Iceland (personal communication, June 6, 2006) for offering us the meaningful phrase "softening suffering" to describe lessening the intensity of suffering. This is now our preferred description rather than "diminishing", "reducing", or "alleviating" suffering, which suggest suffering can be measured, and of course this painful human phenomena cannot be calculated (Wright, 2005).

This book was written primarily for health care providers who work with ill individuals and families, but those who are experiencing illness suffering may also benefit from an understanding about how beliefs can increase illness suffering or invite healing.

How the Illness Beliefs Model Was Developed

Our Clinical Experience and Context

For twenty-five years, our clinical practice has been a central anchor to both our teaching and research that led to the development and refinement of the *Illness Beliefs Model*, as well as to the many practice examples included in *Beliefs and Illness: A Model for Healing*. The clinical practice occurred at the Family Nursing Unit, University of Calgary (1982-2007), a unique outpatient clinic for families suffering with serious illness. Dr.

Lorraine Wright established the clinic in 1982 for the purpose of education, clinical scholarship, and research (Bell, 2002, 2008; Flowers, St. John, & Bell, 2008; Gottlieb, 2007; Wright, Watson, & Bell, 1990; Wright, Watson, & Duhamel, 1985). Faculty and graduate students worked together as a clinical team to collaborate and consult with families to soften emotional, relational, physical, and/or spiritual suffering. Direct involvement in clinical practice enabled us to examine the practice, offer descriptions of the practice, and continuously learn from families. This resulted in the discovery, organization, analysis, synthesis, and transmission of knowledge about caring practices with families experiencing illness (Bell, 2003; Diers, 1995).

The medium of offering healing to families experiencing illness is the *therapeutic conversation*. An extensive database of videotaped therapeutic conversations between nurse clinicians, clinical teams, and families served as the unit of data collection and analysis across our program of research at the Family Nursing Unit (Bell, 2008; Bell & Wright, 2007).

Research about Therapeutic Change

As a clinical team, we were grounded in the everyday complexities and uniqueness of each family we served. While we benefited from the extensive research literature that offered a description of family responses to illness, we were intimately involved in *doing* intervention and consequently became intrigued with questions about the intervention process itself. This kind of research is complicated and comprehensive to design and implement because it is a) discovery oriented, b) attempting to account for a relational process that involves both the clinician and family members, and c) focusing data collection and analysis on more than one individual. The research that underpins the *Illness Beliefs Model* sought to describe, explore, and evaluate our clinical practice to gain an understanding of *what* was working in the moment. What were we as nurses actually doing and saying that was helpful to families in their experience of illness suffering?

The complexity of accounting for what is happening *inside* the intervention was overwhelming. Rather than trying to simplify the phenomena, we rose to the challenge of its complexity and utilized hermeneutic inquiry (Benner, 1994; Chesla, 1995; Gadamer 1960/1989,

1976; Moules, 2002a; Packer & Addison, 1989) to account for what was happening *inside* the therapeutic conversation. We routinely asked families for permission to videotape each therapeutic conversation for clinical learning and research purposes. Over the past twenty-five years we developed a rich data set of videotaped therapeutic conversations, and extensive clinical documentation about each therapeutic conversation, with families who were experiencing serious illness.

The purpose of family nursing intervention is to effect change that will soften suffering and promote family healing; therefore, a beginning step in our program of research was to focus on *significant change events*. In our clinical work with families at the Family Nursing Unit, we have experienced many incredible changes within families that have invited healing and a return to a peaceful and satisfying health status. To understand these changes, we embarked on a funded research project that helped us learn about what accounted for this therapeutic change. Specifically, our research project was entitled "Exploring the process of therapeutic change in Family Systems Nursing practice: An analysis of five exemplary cases." The investigators were Drs. Janice Bell, Lorraine Wright, and Wendy Watson Nelson. Other research team members included Lori Limacher and Dianne Tapp (research assistants), and our consultant Dr. Catherine (Kit) Chesla from the Department of Family Health Nursing, University of California, San Francisco. Our research question was: "How does therapeutic change occur?" Our research team reviewed all the families we had worked with from 1988-1992 and chose five exemplary cases. The family sessions with these selected families were conducted by two expert family clinicians/nurse educators (Drs. Lorraine Wright and Wendy Watson Nelson). In each case, the families showed dramatic cognitive, affective, or behavioral change during the Family Systems Nursing therapeutic conversations, which ranged from two to five sessions. The families also reported improvement in the presenting problem when they were interviewed six months after the completion of the clinical sessions for our Family Nursing Unit outcome study.

Direct observation of the previously videotaped clinical sessions constituted our data set. We first viewed the videotapes to get an understanding of the whole of the clinical work with the family. Next, each member of the research team selected segments of the therapeutic

conversations she considered salient to the process of therapeutic change (Gale, Chenail, Watson, Wright, & Bell, 1996). Each therapeutic conversation was examined to see how the nurse clinician responded to the family and how the family responded to the nurse. The members of the research team then convened to discuss their choice of change segments to see if consensus among team members could be reached. The change segments were then transcribed and interpretive analysis was done on the text of the change segments. Questions were asked of the data such as: What is happening here from the nurse's perspective and from the family's perspective? Is this move or intervention unique or is it similar to another? Has it happened before? Do we have a usual name for this move? What else could we call it?

This process uncovered the personal, contextual, and cognitive processes that form the clinician's formulation of any given case and the overall model of intervention. The study helped us uncover new understandings about our clinical practice approach and gave us a language with which to describe the therapeutic process. Our approach for intervention was described in our 1996 publication *Beliefs: The Heart of Healing in Families and Illness* (Wright, Watson, & Bell, 1996) with translation in Japanese and Swedish.

Research Findings: A Book, and A Model without a Name

The impact of this research project on our practice was substantial. The project illuminated, clarified, and offered new descriptions of our clinical practice that shaped and changed our subsequent clinical work with families at the Family Nursing Unit. Despite the publication of the *Beliefs* book in 1996, we did not give the clinical practice model an actual name, which, in hindsight, was probably a mistake or oversight on our part.

Part of our hesitancy came from humility and perhaps some fear. The discipline of Nursing during this era loved the language of "nursing models," and we frankly did not feel worthy to be included in the list of distinguished contributors. Part of our hesitancy also came from disagreement among our clinical research team. We simply could not agree about the name of the approach and were not sure whether having "therapy" in the name might limit its appeal to some health care providers.

We also wondered if we really wanted to use a staid and somewhat pompous word like "model" to name the clinical practice approach. Over the next few years, we, along with our graduate students, referred to our clinical approach using several names. For a few years it was called "Systemic Belief Therapy" (SBT). Our colleague, Dr. Wendy Watson Nelson, accepted an academic position at Brigham Young University in 1992 and taught scores of family therapy students this clinical approach calling it "SBT" in presentations, publications, and dissertations. Our own graduate nursing students at the University of Calgary affectionately dubbed the approach the "Wright, Watson, Bell" clinical approach and used the acronym "WWB" in their written case studies and conceptual framework papers for several years. By the late 1990s, frustrated with the multiplicity of names, we decided to end the confusion. We daringly named the clinical practice the *Illness Beliefs Model* and were encouraged by a reassuring note from then doctoral student, Dr. Nancy Moules (who later became a Family Nursing Unit faculty colleague). She reminded us that the term "model" was a synonym for "something set before one for guidance or imitation" (Merriam-Webster's Collegiate Dictionary).

The Conversation about the Illness Beliefs Model Continues

Out of many domains of family functioning, the *Illness Beliefs Model* pulls to the foreground an emphasis on beliefs, recognizing that family members as well as health care professionals have beliefs that are both facilitating and constraining in the ways they influence lives, relationships, behavior, illness suffering, and healing (see Chapters 2-6). Beliefs that are constraining can be explored, challenged, and altered (see Chapters 7-9); those that are facilitating can be acknowledged, strengthened, and amplified (see Chapter 10). The *Illness Beliefs Model* is based upon the principle that it is not necessarily the clinical problem or illness but rather *beliefs* about the clinical problem or illness that serve as the greatest source of individual and family suffering; furthermore, beliefs also lie at the heart of individual and family healing.

Within the *Illness Beliefs Model*, the language of "moves" is utilized in addition to interventions for the purpose of underscoring the process and flow that are co-evolved between the clinician and family members. The model is comprised of four macromoves:

- Creating a Context for Changing Beliefs
- Distinguishing Illness Beliefs
- Challenging Constraining Beliefs
- Strengthening Facilitating Beliefs

These macromoves are operationalized through micromoves (or interventions), which are the specific clinical practices that guide therapeutic conversations with families. In view of the diversity of beliefs about the etiology, diagnosis, and prognosis of illness as well as beliefs about the role of family members and health care providers in illness care, beliefs hold significant possibilities for both family suffering and family healing.

In subsequent research and published case studies, the *Illness Beliefs Model* has been described with families experiencing chronic illness (Bell, Moules, Simonson, & Fraser, 2004; Robinson, 1994, 1998; Robinson & Wright, 1995; Wright, 1997); loss and grief (Levac et al., 1998; Moules, 1998; Moules, Thirsk, & Bell, 2006); cardiac illness (Bohn, Wright, & Moules, 2003; Tapp, 1997, 2001, 2004); cancer (Duhamel & Dupuis, 2004); mental illness (Marshall & Harper-Jaques, 2008; Watson & Lee, 1993); violence (Robinson, Wright, & Watson, 1994); and palliative care (Duhamel & Dupuis, 2003). The usefulness of particular interventions within the *Illness Beliefs Model* have been studied from the perspectives of the families who received the interventions and the nurses who offered these skilled practices, including therapeutic letters (Bell, Moules, & Wright, 2009; Moules, 2000, 2002b, 2003, 2009a, 2009b); commendations (Houger Limacher & Wright, 2003, 2006; Houger Limacher, 2003, 2008); spiritual conversations about illness suffering (McLeod, 2003; McLeod & Wright, 2001, 2008); and the "One Question Question" (Duhamel, Dupuis, & Wright, in press). The Family Nursing Unit collection of archived publications is available for public access on DSpace at the University of Calgary Library: *https://dspace.ucalgary.ca/handle/1880/44060*. (For a list of publications by Dr. Lorraine M. Wright and/or Dr. Janice M. Bell and other faculty and graduates associated with the Family Nursing Unit, please see Part III, Resource One.)

Through numerous professional workshops and graduate courses, Family Nursing Externships, and conference presentations, the *Illness*

Beliefs Model has been taught to thousands of graduate students, academics, and health care providers in Australia, Brazil, Canada, Chile, Finland, Japan, Hong Kong, Iceland, Italy, Israel, Germany, New Zealand, Portugal, Poland, Singapore, Scotland, Spain, Sweden, Switzerland, Thailand, Viet Nam, and the United States. Part III, Resource Two, provides a listing of the international application, implementation, and dissemination of the *Illness Beliefs Model* in publications related to research and clinical practice authored by our colleagues and/or their students.

Conclusion

Understanding illness suffering through a systemic, relational lens is the first step to expanding healing opportunities and inviting innovative approaches to health care with not only individuals but families and larger systems as well. *The Illness Beliefs Model* is a clinical practice model for health care providers who care for families experiencing serious illness. Developed from clinical scholarship and a modest program of research at the Family Nursing Unit, University of Calgary, the *Illness Beliefs Model* uncovers and expands the therapeutic possibilities for helping and healing families who are suffering in their experience of serious illness. This clinical practice model has been introduced to numerous international health care providers over the past twenty-five years. *Beliefs and Illness: A Model for Healing* offers an expanded view of the 1996 publication of *Beliefs* with further embellishment of the model and inclusion of recent research and clinical practice examples.

In the chapters that follow, we will elaborate on the central focus of illness beliefs (Part I: Chapters 2-6) and then describe in detail how health care providers can use the *Illness Beliefs Model* to soften illness suffering in individuals and families and promote individual and family healing (Part II: Chapters 7-10). We have invited our Family Nursing Unit colleague, Dr. Nancy Moules, to offer the final chapter in Part II that features her astute clinical application of the *Illness Beliefs Model* to a special population: families who are grieving (Part II: Chapter 11). Finally, Part III of this book offers additional resources related to the *Illness Beliefs Model.*

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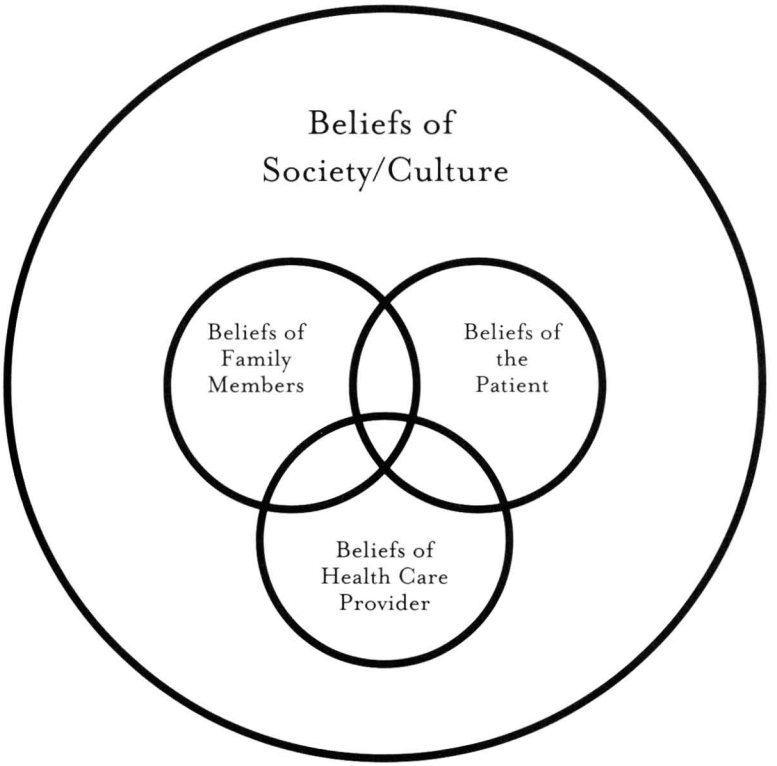

Figure 1: Illness Beliefs Model—Intersection of Beliefs