

〔特別講演〕

Suffering and Family Nursing Intervention Research : A Healing Combination *

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INTRODUCTION

Within nursing, interventions are those healing practices that can diminish or alleviate suffering for individuals and families encountering serious illness. Therefore, intervention research should be the emphasis and focus of family nursing research (Wright & Bell, 1994). I believe that it is imperative that we connect the importance of intervention research with suffering. However, a family nurse researcher immediately encounters significant challenges when embarking on research about interventions and suffering. How can the profound, human experience of suffering, particularly the suffering that accompanies serious illness, be fully appreciated when examining interventions? What contributes to the dearth of evidence-based practice about family nursing interventions that contribute to the alleviation of suffering? What nursing behaviors can potentially enhance suffering?

Perhaps the two most difficult questions for family nurse researchers are: "Can the profound experience of suffering be researched? (Frank, in press). And conversely, can research contribute to further suffering?"

Illness and Suffering

Serious illness invites a wake-up call about life. Seri-

ous illness comes in many forms such as chronic, life threatening, or mental illness. It arouses the need to be known, to be heard, and to be validated—the need to know that one's life matters in the life of someone else and that the life one is living and has lived is and has been worthwhile (Frank, 1994). These needs fuel the telling of individual and family members' experiences with illness. And these illness experiences have become known as illness stories or narratives (Kleinman, 1988).

It is within these illness stories that suffering looms. Suffering means to experience, undergo, or tolerate anguish, grief, loss, and/or unwanted or unanticipated change. This type of suffering within the context of illness needs to be told and talked about. However, too often patients and family members are encouraged to only tell their medical story or narrative (i.e., to discuss the disease or condition, complete with medication, dosages, and tests).

The illness narrative (i.e., the suffering that is being endured and the effects of this suffering) is rarely brought forth in conversation by nurses. For example, questions like the following are seldom asked: What changes, if any, have there been in your life since you were diagnosed with breast cancer? What has been the effect of this illness upon your marriage, your family? These questions address the suffering that is being endured and the systemic effects of that suffering. Sometimes, questions can be even more specific about suffering by simply asking: "Who in the family is suffering the most?" The responses to these types of questions

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quickly confirm that suffering IS the illness experience.

Suffering is raw, personal, and deep. Suffering is not partial to any particular gender, race or religion, spares no one, and favors no one. Suffering greets the young as well as the old. And suffering has a very demanding dimension. It continually begs for explanation. Explanations about why suffering has occurred and how can it be endured?

Explanations about suffering also beg answers to the meaning of a reduced quality of life or the potential shortening of one's life. As Frank (1994) suggests, the primary lesson that the ill has to offer is the "pedagogy of suffering". These teachings compel us to offer healing nursing practices that relieve suffering and conduct research to further our knowledge about what nursing practices actually do diminish or relieve suffering.

To conduct research about suffering, we must first acknowledge the dramatic difference in daily living between nurses and those in their care. The seriously ill and their family members live in a world that is profoundly dissident from nurses. The ill and their family members live in a world where suffering becomes a constant companion, and frequently a tormenting and agonizing companion. This suffering manifests itself in many ways. For example, strained family relationships, forced exclusion from everyday life, and the loss of one's former life become commonplace.

The alleviation of suffering has always been the cornerstone of caring. Suffering gives "caring its own character and identity, and all forms of caring aim, in one way or another, to alleviate suffering" (Lindholm & Eriksson, 1993, p. 1354). But what IS the best way to care for those that are suffering? What do the seriously ill and their family members' convey about their suffering in conversations with health professionals?

Listen to the suffering of a woman in her late forties experiencing the serious illness of Amyotrophic Lateral Sclerosis (ALS). "I have suffered so many losses. In the

eight months since my diagnosis, my legs, left hand and arm are paralyzed and my right hand is deteriorating. My capability of speech is gone and I am having trouble swallowing. I depend on everyone to do almost everything for me. But this is just the summary of the physical list. What I have really lost is me! It is like everything I love is being moved out of my reach. Yet, I am still here in the presence of my life, but unable to participate".

But suffering does not occur in a vacuum or in isolation. Suffering is linked to and intertwined with the beliefs that one holds about their illness (Wright, Watson, & Bell, 1996). A belief is the "truth" of a subjective reality that influences biopsychosocial-spiritual structure and functioning (Wright et al, 1996). Individual beliefs of patients and family members are involved in both the experience of suffering and in making inferences of suffering. Certain beliefs may conserve or maintain an illness; others may exacerbate symptoms; others alleviate or diminish suffering. For example, what family members and nurses believe about their prognosis, diagnosis, or treatment and healing can enhance or diminish suffering.

In an eloquent and illuminating description of his illness experiences, Frank (1994) offers his idea of how persons make meaning of their suffering. He asserts that people tell stories of their illness to make sense of their suffering; and when they turn their diseases into stories, they find healing.

Suffering leads one into the spiritual domain as the big questions of life are faced (Wright, 1999; Wright et al, 1996). Questions such as "Why has this illness happened to me?" "Why do some people die before their time?" "What am I supposed to learn from this suffering?"

Many beliefs and ideas exist about the purpose, lessons, and reasons for suffering. The medical perspective claims that suffering occurs in response to pain

and illness; occurs as a response to the meaning of symptoms, and occurs when the impending destruction of the person is perceived and to remove the threat is to remove the suffering (Morse, 2000).

Addressing the issue of what lessons can be learned from suffering, Anne Morrow Lindbergh writes: "I do not believe that sheer suffering teaches. If suffering alone taught, all the world would be wise since everyone suffers. To suffering must be added mourning, understanding, patience, love, openness and the willingness to remain vulnerable."

Theological perspectives suggest that suffering has redemptive and transformative qualities. For example, Whitney (1966) attempts to put a more kindly face to suffering by suggesting certain benefits. "No pain that we suffer, no trial that we experience is wasted. It ministers to our education, to the development of such qualities as patience, faith, fortitude and humility. All that we suffer and all that we endure, especially when we endure it patiently, builds up our characters, purifies our hearts, expands our souls, and makes us more tender and charitable" (p. 211).

Suffering does change us, and usually for the better. Frequently, we have a deepened compassion, a more tender heart, or become less judgmental. But suffering can also invite bitterness over losses, confusion about life's abrupt changes, anger over what might have been, and even competitiveness over what type of suffering is the most severe.

The experience or depth of one person's suffering is never the same as another's. Suffering experiences cannot be compared, but unfortunately comparisons are made about which sufferings we believe are the most horrific. Is breast cancer of a young 33 year old mother more devastating than a brain tumor of a 10 year old boy?

One philosophical belief frequently offered to those suffering with illness is that "life could be worse". This

belief is offered to provide comfort and encouragement. One woman, suffering from endometriosis, did not find this belief useful, however. She responded: "I know life could be worse. I could have only one eye or leg, and I am very fortunate to have all I do have... But those philosophies do not solve the disease, do not get rid of the pain, the tears, the frustrations, or the heartaches that come with the problems" (Donoghue & Siegal, 1992, p. 55).

This particular suffering experience call for nurses to recognize that each person's suffering is unique and that attempting to have persons "count their blessings" can inadvertently trivialize suffering from illness.

Through highly privileged conversations between nurses and family members, it is readily acknowledged that suffering, beliefs, and spirituality are close cousins (Wright, 1999). They are so intertwined that it becomes difficult, or near impossible, to discuss or attend to one without attending to the others.

But I submit that reducing or diminishing suffering is the center, the essence, and the heart of nurses' clinical practice. Therefore, the ethical and obligatory goal of nursing must be to reduce, diminish, or alleviate (and hopefully heal) emotional, physical, or spiritual suffering of patients' and their family members'.

I believe that alleviation of suffering has always been the heart of nursing but not recognized as such. Conversations about suffering are not routinely brought forth in nurses' encounters with families experiencing serious illness.

But suffering does not just affect the person experiencing the illness. Illness is a family affair and all family members suffer. If nurses would embrace just this one belief, that illness is a family affair, it would change the face of nursing practice (Wright & Leahey, 2000) and minimize suffering. No one person in a family experiences cancer, epilepsy or heart disease. All family members are influenced by the illness and reciprocally,

all family members can contribute to the healing of an illness.

On a personal note, if nurses had embraced the belief that illness is a family affair and consequently all family members suffer, it would have provided much needed healing for my family and me. During my Mother's 5 year ordeal with Multiple Sclerosis (MS), she received competent caring by nurses, physicians, and other health professionals for her physical suffering. But my Mother's emotional and spiritual suffering was rarely addressed. And the suffering of my father, other family members, and my own, was never addressed by nurses. During the last year of my Mother's life, she had become a quadriplegic and experienced frequent severe pain in her hands. After one telephone call from my Father, I was so struck by his words that I wrote them down. "We were having a great day until the pain returned—now nothing seems to be helping. I've given your Mother all the pain medication and more that I can. I'm rubbing her hands with that new ointment. It's very tough to watch her suffer. I've lost my appetite and won't be having supper tonight—besides I couldn't leave your Mother alone in this pain". Is illness not a family affair? Who was suffering the most emotionally, my Mother or my Father? And who the most physically?

From this brief discussion about illness and suffering, I would like to encourage, no admonish, family nurse researchers to give more attention, emphasis, focus, and time to research suffering. I do not believe that we need more research studies that describe or define suffering.

Janice Morse and her colleagues in Canada have given much research effort to better understand the concept of suffering. One such study examined the concept of suffering and enduring and also provided a framework that illustrated the interrelationships between these two distinct states (Morse & Carter, 1996).

This study identified a dynamic movement between enduring and suffering, dependent on the person's innate ability to handle the emotional work of suffering. Their study raised questions that could, from my perspective, be answered by examining actual clinical practice. For example, they raised the question of "what moves a person from enduring to suffering or from suffering back to enduring?"

More recently, Morse and Penrod (1999) have attempted to link the concepts of suffering, enduring, uncertainty and hope to construct a comprehensive model for understanding and interpreting clinical situations.

While all of these efforts can assist with our understanding of suffering, I believe that the best way to understand suffering is to examine conversations of ill sufferers and their nurses. Frank (in press) boldly suggests that "too much research on illness rewrites their /our lives as behavior to be explained: coping, giving and receiving support, denial, adherence (the more politically correct name for the old compliance), even grieving all become behaviors to be explained as functional and adaptive with reference to clinically normative standards" (p. 16). It might also be added that too much research on the behaviors of those who suffer may not alleviate but inadvertently contribute to suffering.

Therefore, family nursing research needs to specify the beliefs and meanings of suffering so that these may be challenged to lessen suffering (Wright et al, 1996). Janice Morse and Joy Johnson (1991) also suggest that not only should the primary goal be to reduce suffering of the ill person and/or the shared suffering, but that it will also increase well-being!

Research, Suffering, and Family Nursing Interventions

If suffering is the center of nurses' clinical practice with families, what family nursing interventions are

the most useful to assist families? What does current nursing research presently indicate about family nursing interventions that could contribute to the alleviation of suffering? What further research needs to be done?

To date, most research has revealed descriptions of the experience of suffering and what has NOT been done to alleviate suffering. In a study by Hinds (1992), the suffering of family caregivers of non-institutionalized cancer patients revealed descriptions such as fear of loneliness, uncertainty about the future, communication breakdown, and lack of support.

Spouses of women experiencing chemotherapy reported suffering themselves during their partners' illness (Wilson, 1991). As these husbands struggled to buffer their wives from the effects of chemotherapy, they also struggled to maintain control of their own feelings of helplessness. They perceived that they were "kept in the dark" and had the perception that the lack of communication with their wives and with health care providers increased their feelings of helplessness and powerlessness, and ultimately these husbands suffered more. Some of the husbands wished they had been able to talk to someone else, particularly an outsider, and they recognized that remaining silent had impeded their ability to cope with the cancer experience.

What can be said about the most difficult questions for family nurse researchers and clinicians: "Can the profound experience of suffering be researched?" (Frank, in press). Can research contribute to further suffering? Frank (in press) argues that some aspects of suffering remain unspeakable. However, I believe the speakable portions of suffering may be lessened when there is acknowledgment, witnessing, or deep listening of the ill person. For suffering to be lessened, nurses must be willing to encounter suffering with ill persons and their family members. Engagement and

suffering are essential aspects of responsible caregiving (Schultz & Carnevale, 1996).

I believe that suffering can be researched without contributing to further suffering if we fully engage with our clients and family members in their suffering. Wilson (1991) asks the poignant question in reporting her research: "How does the researcher listen to such suffering and remain detached?" I submit that remaining detached does not allow one to know, understand, or research another's suffering.

Why would we as nurse researchers, or clinicians, or educators want to remain detached from another's suffering? I am familiar with the arguments that researchers offer about the need to remain detached and distant from the topic and subjects being researched. Could our research not take on a more human and humane dimension if we allowed ourselves to be touched and moved by suffering?

I also believe that the experience of suffering can be better understood by conducting a particular kind of research following a particular kind of practice. I do not believe that we need to have further studies about the lived experience of suffering before we can intervene.

With my colleagues Drs. Wendy L. Watson and Janice M. Bell, we have evolved a clinical approach, namely the Illness Beliefs Model, to working with families where a member is seriously ill (Wright et al, 1996). We emphasize the altering, challenging, or modifying constraining beliefs as one way to assist with alleviating or diminishing suffering in families. Some of the ways we have found useful in alleviating suffering are acknowledging suffering; inviting, listening to, and witnessing suffering; connecting suffering and spirituality; recognizing and challenging our own constraining beliefs; creating a healing environment; and inviting reflections about suffering (Wright, 1999, Wright et al, 1996).

We are now embarking on a research project that will examine the conversations of suffering between nurses and families experiencing serious illness. Specifically, we wish to understand the nature of those illness conversations when suffering is brought forth.

For example, what influence or connection do illness beliefs have upon suffering and vice versa? We are also curious about what influence or connection do family members' and nurses' notions of spirituality have upon their suffering? The potential contribution of this research is to continue advancing our knowledge about living with and suffering from serious illness. Through this examination of clinical nursing practice, clearer ideas of how to assist families suffering with illness will be evident. If a better understanding of what aspects of these conversations can potentially heal suffering, then the importance of routinely inviting these conversations of suffering and involving family members in healthcare can be further advocated and admonished.

This research will also point the direction for the necessary knowledge and skills required by nurses to assist in the very ethical and obligatory endeavor of assisting individuals and family members who suffer with serious illness. This is one example of the kind of research that may be conducted that moves beyond defining and describing suffering. It is time to research what specific nursing interventions in our conversations of suffering create the conditions for healing to occur.

In our clinical work in the Family Nursing Unit (FNU), University of Calgary, we believe that creating a trusting environment for therapeutic conversations invites open expression of family members' fears, anger, and sadness about their illness experiences (Wright et al, 1996). Through this trusting environment for the expression of strong affect contributes to reducing suffering.

Current family nursing research studies conducted

at the FNU are beginning to illuminate what particular family nursing interventions are healing and diminish suffering. Robinson's (1994) study examined the process and outcomes of interventions with families experiencing chronic illness. Her study revealed that "the two major components of therapeutic change from the families' perspective are: creating the circumstances for change and moving beyond/overcoming problems" (p. 99). Specifically, the nurses' acts of bringing the family together and creating a sense of comfort and trust were the fundamental behaviors that enabled family members to convey their illness experiences. By providing a context for sharing among family members of their illness experiences, intense emotions are legitimized. Expressing the impact of the illness on the family and, reciprocally, the influence of the family on the illness, gives validation and voice to their experiences and thereby are healing practices that reduce suffering.

Tapp (1997) explored the therapeutic conversations between nurses and families experiencing ischemic heart disease within the FNU. These therapeutic conversations moved beyond social conversations and were purposeful, deliberate, and healing. She uncovered that the conversations between nurses and families were about healthy lifestyles; family support; uncertainty and death. These therapeutic conversations created the conditions for healing to occur. By engaging in these particular types of conversations with families experiencing heart disease, suffering was diminished.

The most recent study by Moules (2000) explored the use of therapeutic letters within the clinical practice at the FNU. Her findings suggest that therapeutic letters written by nurses and mailed to families following family meetings have the potential for further healing and minimizing suffering. By commending patients and family members' on their strengths in the midst of ill-

ness, asking reflective questions, and expanding the therapeutic relationship all serve to create a context for healing.

All of the aforementioned studies of particular nursing practices and interventions are, I believe, revealing and bringing forth conversations of suffering. By bringing forth these types of conversations, we are acknowledging that suffering exists. These research studies conducted within the FNU strongly suggest that it is not just a good thing or a nice thing to provide opportunities for families to have conversations about their suffering. It is necessary and imperative for healing to occur!

Family nurses must have as their primary goal to create an environment for alleviating and/or healing emotional, physical, and spiritual suffering (Wright, 1997, 1999; Wright et al, 1996).

Research Presentations and Publications about Suffering

In our presentations and publications, we must truly honor those who suffer with illness and who graciously participate in our research studies. We can do this through our tone, affect, and manner in our presentations and publications and show congruence between the research findings and our response to them.

We must assure that illness sufferers and their family members have not gone unheard. We can do this by acknowledging and affirming that we have been touched and softened by those who suffer. Research about how to comfort and heal those who are suffering must not matter just in the moment of a conference presentation, or a professional publication. It must matter in our nursing practice.

Research that addresses the ill addresses suffering. Therefore our research findings, conclusions, reflections, and discoveries must illuminate suffering and how to heal, diminish, or alleviate suffering. Most importantly, our research findings must be offered in a

manner that will be taken up in nursing practice.

CONCLUSION

Hopefully, family nurse researchers who examine interventions utilized with families will become more committed and attuned to the marvelous potential for healing that their research studies possess for those who suffer with or from serious illness. And in this research process, we can reaffirm and reclaim our desire and motivation to be healers to those who suffer.

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