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# Perceptions of the Role of Nurses in Providing Psychosocial Care for Patients with Cancer

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Kerry Suzuki

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Abstract

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# Abstract

Psychosocial care for patients with cancer is aimed at detection, diagnosis, treatment, and prevention of psychological distress (PD). PD is a universal clinical phenomenon experienced by at least 38% of patients with cancer, yet only10% are identified as having PD. Nurses are presumed providers of psychosocial care, yet no research examined what nurses perceive as their role in caring for patients with cancer, and whether nurses believe that providing psychosocial care to patients with cancer is within their role. Patient care that rests on assumptions is too precarious; nurses' role beliefs are critical in light of their impact on practice and psychological distress. Accordingly, a multinational sample of 10 nurses was snowball recruited for this focus group study to discuss prior research findings on psychological distress and the role of the nurse. Lazarus's cognitive motivational relational theory informed the study. Discussion narratives were coded for psychosocial care, role beliefs, barriers, and solutions. Provider domains were analyzed using Burnard's content thematic analysis method. Results indicated that nurses' role beliefs could not be determined as a barrier to psychosocial care; providing psychosocial care for all patients in all diagnoses was claimed as fundamental nursing work. However, nurses' current psychosocial care practice may fail to detect, treat, or prevent psychological distress, even in the absence of structural barriers. Nurses' psychosocial care appears to lack reflection on its clinical significance. Implications for social change include improving psychosocial care for patients and survivors of cancer that could result in improvements in quality of life.

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# Dedication

This work is dedicated to Jan Phyland Grainger (1953-2005).

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# Chapter 1: Introduction to the Study

## Overview

Psychosocial care for patients with cancer is primarily aimed at detection, diagnosis, and treatment of Psychological Distress (PD). PD is a clinical phenomenon that is experienced by at least 38% of patients with cancer (Holland, 2002, p. 85, 2004; Pirl, 2004) yet evidence suggests that only 10% of these patients get the help they need (Holland, 2004;McCorkle, 2003). International research has focused on structural barriers to psychosocial care but there is a dearth in the literature on the provider role. Nurses are presumed providers of psychosocial care, yet no research has examined nurses' perceptions of their role in caring for patients with cancer.

To address this gap, this focus group accomplished two goals. First, it identified nurses' beliefs about their role in providing psychosocial care to patients with cancer. Second, it determined whether these role beliefs are a barrier to psychosocial care. Role beliefs are defined as opinions held by nurses concerning the professional role of the nurse. Because nurses' role beliefs determine clinical practice, it was important to understand nurses' role beliefs about providing psychosocial care to patients with cancer to determine if these role beliefs are also a barrier to psychosocial care. This study provided culturally diverse perspectives on the role of the nurse given its multinational sample of nurses. Two groups of nurses participated in this study, and their data were analyzed using thematic content analysis.

## Background of the Study

PD in cancer is a universal clinical phenomenon that affects between 25 to 50% of patients with cancer (Holland, 2002, p. 85, 2004; Pirl, 2004). Suicide, which has been associated with PD, is not an uncommon outcome of psychological distress (Clarke & Kissane, 2002; Halldorsdottir & Hamrin, 1996; Schairer et al., 2006). In order to help prevent psychological distress, psycho-oncologists have recommended that cancer care include both medical and psychosocial care referred to as *integrated care,* and involve all health care professionals (Holland, 2002, 2004; McCorkle, 2003). Integrated care has received growing approval in recent years. Although psychotherapeutic interventions alone have not been shown to increase cancer survival (Boesen & Johansen, 2008), it has been shown to reduce pain (Butler et al., 2009). The National Health and Medical Research Council (NHMRC) of Australia published a set of clinical guidelines for the psychosocial care of patents with cancer (National Breast Cancer Centre & NCCI, 2003) to assist and encourage integrated care by all health care professionals. These guidelines are based on the evidence that psychosocial care results in fewer medical visits and is therefore cost effective (Carlson, 2008).

Psycho-educational interventions have preventive potentials that could easily be integrated into daily nursing care (Graydon, 1984; Towers & Berry, 2007; Valente, 2007). Given that patient education is already a component of nursing care, there is justification for nurses taking on a greater role in that domain (McCorkle, 2003). PD carries existential undertones that draw on nurses own fears of mortality (Haavardsholm & Naden, 2009) yet in accordance with nursing philosophy (Benner, 2006) psychosocial care for PD necessarily requires that nurses would attend to both physical and psychological pain as they provided individualized care (NHMRC, 2003) to their patients with cancer. Although there is the expectation that all nurses will and should provide psychosocial care, it is unclear where nurses stand on this point.

## History of the Study of Psychological Distress

PD has only recently been recognized as a clinical phenomenon. Early studies suggested that cancer per se was simply a “non adaptation syndrome” whose rate of progress depended on personality characteristics of the person so diagnosed (Blumberg, West, & Ellis, 1954). This implied that individuals had both a physical and psychological predisposition to cancer whereby the emotions and psychosocial factors played some role in the cause and development of cancer (Schmale & Iker, 1966). Later researchers reported that one-fourth of patients with advanced cancer experienced depression (Plumb & Holland, 1977, 1981). Weisman and Worden’s (1976-77) *Existential Plight* described the first 100 days from diagnosis, wherein the patient experienced intense anxiety and fear of death that resulted in severe PD. This stage generally passed with time and adjustment but could potentially progress into clinical distress; therefore each patient’s response to cancer was to be acknowledged and promoted as unique. Further research reported that women with breast cancer who experienced distress prior to surgery tended to experience prolonged distress post surgery (Morris, Greer, & White, 1977) although a patient’s “ego strength” correlated with her levels of distress (Worden & Sobel, 1978, p. 589). A previous psychiatric morbidity was claimed as a predictor of distress (Plumb & Holland, 1981). According to Lansky et al. (1985), the methodology explained the range in rates of distress. Rates of distress varied widely from 15 to 70% in the early studies that included hospitalized patients and outpatients. These findings were confusing because of the difficulty in distinguishing how pain and disability might influence PD (Lansky et al., 1985). According to some (e.g. Carney, Jones, Woolson, Noyes & Doebbeling 2003; Davies, Davies, & Delpo, 1986), head and neck cancers are associated with higher levels of distress. This was presumed due to communication problems and their subsequent negative impact on patient self-esteem (Carney et al. , 2003; Davies et al., 1986). Recognition of distress as a clinical condition was also made difficult by the limitations to clear diagnosis. For example, early versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) DSM-III and IV reportedly did not include the possibility for symptoms that might reflect the illness itself (Razavi, Delvaux, Farvacques, & Robaye, 1990). Later researchers ruled out false positives with the Hospital Anxiety Depression Scale (HADS) (Zigmond & Snaith, 1983). False positive were to be expected because both depression and cancer treatment caused similar symptoms, namely sleep disturbances, weight loss, fatigue, and anorexia (Pasquini & Biondi, 2007). Recent instruments used to screen for overall distress have included the Distress Thermometer (Bultz & Holland, 2006; Holland, 2007) and the 18-item Brief Symptoms Inventory (BSI-18)(Zabora et al., 2001), The Johns Hopkins Brief Symptom Inventory, and Functional Assessment of Cancer Therapy (FACT-G) scale (Cella, Tulsky, & Gray, 1993; Clark, 2001). Pasquini and Biondi (2007) also claimed the modified version of the DSM-IV was useful for evaluating major depressive disorder in patients with cancer, although Akechi and his colleagues (2009) claimed the DSM-IV was less helpful in helping clinicians identify the severity of depression. According to Zabora, Brintzenhofeszoc, Curbow, Hooker and Piantadosi (2001), constructed instruments have consistently illustrated that between 25 and 50% of patients with cancer experienced PD at some time in their cancer experience. A recent critical review of depression in cancer also claimed a range of between 20 and 50% of cancer patients by Pasquini and Biondi (2007). who cited findings of an observational cohort where 33% of 222 women with early breast cancer experienced major depressive disorder (MDD) at the time of diagnosis, 10% experienced MDD after one year, and 45% experienced MDD at recurrence. Variations in these ranges were due to assessment timing differences, cancer site, age, and gender. Based on the current literature on the prevalence of PD in cancer, at least one quarter of cancer patients could be expected to experience clinical levels of PD.

Some level of distress for some period of time was acknowledged as a normal reaction to cancer and its treatment (Massie, 2004; Weisman & Worden, 1976-77; Zabora et al., 2001). However, distress was not related to the severity of the cancer, even in patients with advanced cancer (Teunissen, de Graeff, Voest, & de Haes, 2007). It was the persistence of this distress that became the focus of concern. This focus was based on findings that even after the so-called “adjustment” to illness some patients continued to experience depression and anxiety at higher rates than in the general population (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). Subsequent research began to narrow down PD as a clinical phenomenon. The history of psychiatric morbidity, availability of social networks, socio demographics status, and comorbid illnesses were cited as predictors of PD (Andersen, 1994; Andersen, Andersen, & DeProsse, 1989). The greatest predictor of PD, according to Zabora et al. (2001), was the level of distress a patient experienced within the first two weeks of care, from diagnosis onward. According to Akechi et al. (2006), the patient's level of distress immediately after diagnosis was a reliable predictor of later distress. Akechi et al. substantiated Weisman and Worden's (1976-1977) *Existential Plight*, that the first 100 days were a decisive factor in the trajectory of PD.

Studies with cancer outpatients reported high levels of anxiety and depression, although age was not necessarily a predictor of distress in this population. Women reported higher levels of anxiety than men. Both men and women reported similar levels of depression (Pascoe, Edelman, & Kidman, 2000). Suicide and suicide ideation have been well-documented possibilities for cancer patients suffering from PD (Miller & Massie, 2006). Cancer patients were considered to be at an increased risk for suicide compared to the general population (Pirl, 2004) and although this risk could lessen over time depending on the type of cancer (Yousaf, Christensen, Engholm, & Storm, 2005) the risk of suicide persisted for 25 years in some breast cancer patients (Schairer et al., 2006). Pirl (2004) studied some 350 studies undertaken between 1966 and September 2001 on depression in patients with cancer, and found that between 10 and 25% of cancer patients suffered from major depressive disorder. Depressive symptoms were experienced by 21% of cancer outpatients and by 3.5 to 17% of cancer survivors. Despite the nuance of having overcome cancer that underlie the terms *survivor* and *outpatient* (McKenzie & Crouch, 2004), Pirl illustrated that psychological distress beyond the acute medical care stage remains a possibility for many in the cancer outpatient and cancer survivor population.

The studies outlined in the above paragraphs summarized the shift in interpreting PD in patients with cancer. Originally seen as a to-be-expected, short-lived illness. PD was later recognized as a potentially serious clinical phenomenon that at least one quarter of patients are expected to experience. According to Thomas and Bultz (2008), the implications of unaddressed PD explained why researchers from the National Cancer Institute in the United States, the Canadian Ministry of Health, and Australia's National Medical Research Council in association with Australia's Breast Cancer Council have all published similar clinical practice guidelines for the psychosocial care of adults with cancer (NHMRC, 2003). These guidelines for all health professionals are justifiably considered testimony to the medical, social, and fiscal impact of psychological distress including its potential for prevention. As a potential barrier to treatment compliance (Rapoport, Kreitler, Chaitchik, Algor, & Weissler, 1993), and through its links to major depression, PD can impact cancer survival (Akechi et al., 2009; Brown, Levy, Rosberger, & Edgar, 2003). Brown et al. found depression at the 15 to 25 months post diagnosis point. Their finding substantiated the argument for stress hormones and immune function changes normally activated in prolonged stress, as possible mechanisms for the depression and reduced survival relationship (Brown et al., 2003; Sephton, Sapolsky, Kraemer, & Spiegel, 2000).

Important to this proposed study are estimates that cancer incidence is on the rise (Parkin, Bray, Ferlay, & Pisani, 2005), which alludes to a similar increase in PD. Based on my review of the literature, PD has been studied internationally. Despite international studies that indicate PD is a universal finding, psychosocial care is not an integral part of cancer care at this time (Mehnert & Koch, 2005), although integrated care is becoming recognized as an important and necessary approach (Muriel et al., 2009; Vitek, Rosenberg Quinn, & Stollings, 2006). According to Holland (2004), even though 38% of patients experience high levels of distress, less than 10% of patients are likely to receive the necessary psychosocial intervention due to a number of barriers. Current concern for improving psychosocial care for patients with cancer has meant that helping to prevent PD has become the business of all nurses. As such, nurses' understanding of psychosocial care and this provider role expectation requires more assessment. Based on my review of available scholarly literature and my own nursing experience, nurses' role beliefs about providing psychosocial care warrant a position in the barriers research because of their connection to clinical practice and current structural barriers.

## Problem Statement

Nurses reportedly experience substantial barriers to providing psychosocial care. These barriers include time, workload, (Botti et al., 2006) lack of patient privacy (McCaughan & Parahoo, 2000), lack of education, and personal anxiety due to their lack of education and skills (Morita et al., 2006; Morita, Miyashita, Kimura, Adachi, & Shima, 2004), Current barriers research focuses on organizational barriers and calls for structural change so that nurses can provide psychosocial care (Kenny, Endacott, Botti, & Watts, 2007; McCaughan & Parahoo, 2000). It is argued however, that current barriers research runs the risk of portraying an overly simplistic view of barriers because it focuses on structural changes that block psychosocial care, and subsequently makes the assumption that nurses "would if they could" provide psychosocial care, but for these structural barriers. The need for psychosocial care is not in doubt. Nor is the need for structural change if patients are to receive the care they need. Rather, it is more a question of ensuring a solid and inclusive approach to understanding barriers and their solutions. Research should include individual nursing care actions and nurses' role beliefs: Do nurses consider it part of their professional nursing role to provide psychosocial care to patients with cancer? These role beliefs likely drive clinical practice. Inductively, health outcomes are a reflection of the interaction of role beliefs and clinical practice, pertinent social and contextual influences notwithstanding. However, there was a dearth of research findings on nurses' role beliefs with respect to psychosocial care. Nurses' role beliefs are anecdotally assumed but this places patients in too precarious a position given the potential outcomes of PD. Nurse's role beliefs require empirical exploration to reduce current structural barriers (Botti et al., 2006; Morita et al., 2004; 2006). Decisively, as determinants of care, nurses' role beliefs have clinical significance for current nursing practice (NHMRC, 2003), and may perpetuate current organizational barriers. Nurses are implicitly presumed to provide psychosocial care but do nurses believe they have a role in providing psychosocial care?

Publications from cancer networks have stated that "attitudes and beliefs of health care professionals will affect clinical care," according to Australia's National Health Medicine Research Council (NHMRC, 2003, p. 5). Nurses reportedly value psychosocial care in general and worry about their self-acknowledged educational deficits (McCaughan & Parahoo, 2000) but do they believe they have a role in providing psychosocial care beyond *comfort* care? Comfort care is one component of psychosocial care but its focus is on physical care tasks. Psychosocial care is seen as systematic formalized care designed to detect, address, and help patients combat psychological distress and may also include discussion with the patient about referral to mental health professionals as needed (NHMRC, 2003).

By reflecting problems back into the nurse arena, the fundamental attribution error becomes relevant. Ultimately, unless nurses see themselves or are educated to see themselves as essential players in integrated care, nurses' self-perceptions may become barriers to psychosocial care. Identifying those perceptions may direct educational curricula by disclosing the starting point for greater nurse involvement in psychosocial care.

## Purpose of the Study

This focus group design identified nurses' role beliefs about providing psychosocial care to patients with cancer. It also determined the role of nurse perceptions in providing psychosocial care. Two groups were comprised of 5 nurses experienced in caring for patients with cancer.

## Nature of the Study

A focus group design study was used to identify nurses' beliefs about the role of the nurse in providing psychosocial care to patients with cancer. This sample of multinational nurses provided different cultural perspectives on role beliefs (Sandelowski, 1995) and provided valuable data for nurses working in multicultural patient populations (Chiang Hanisko, Ross, Ludwick, & Martsolf, 2006; Freda, 1998;

Mehnert & Koch, 2005). Data analysis consisted of thematic content analysis (Burnard, 1991). I will discuss the sample and method of data analysis in detail in chapter 3.

Following institutional permission, I invited nurses from a locally situated multinational nursing association that includes nurses from Africa, Asia, Australia, North America, Europe, and Middle East to form the focus groups. These nurses were experienced in caring for patients with cancer. Focus groups comprised of 5 participants is considered acceptable for generating interaction and discussion (Sandelowski, 1995). The study's major research questions and previous research findings on psychological distress, psychosocial care, current barriers and, the role of the nurse were used to guide the interviews (Rubin & Rubin, 2005). I discuss the research questions in detail in chapter 3 and provide an outline of the guiding questions as follows:

1. What do nurses believe is their role in the care of patients with cancer?
2. Where do nurses' role beliefs originate? Within nursing education curriculum, social expectations based on the traditional image of the nurse, or in individual nurse expectations acquired and developed with experience?
3. Previous barriers research cited workload, time, education, and patient privacy as barriers to providing psychosocial care. How might these barriers be ranked? How might these barriers be overcome?
4. How relative is the cancer diagnosis per se to the organizational barriers that block psychosocial care?

Two overarching questions also guided this study: How can patients with cancer be sure they can get the psychosocial help they need? What does it take for nurses to take on a greater role in providing psychosocial care? The venue location for the interviews was set on the agreed upon convenience of the participants and me (Morse & Field, 2002). The time frame for collecting and analyzing this data was six months. Data transcription and field notes analysis were undertaken immediately after collection (Rubin & Rubin, 2005). I discuss the methodology for this study in detail in chapter 3.

## Significance and Rationale

The significance and rationale of this study lay with current nursing practice and its theoretical relevance to PD given the seriousness of possible outcomes, including patient suicide (Schairer et al., 2006). PD is medically, socially, and economically costly yet preventable, as indicated by the recommendations in the clinical guidelines cited above.

Current barrier research has focused on organizational structures that block psychosocial care. This emphasis on structural barriers may lead to the pervading belief that organizational barriers alone block psychosocial care. This study departs from previous barriers research by its focus on nurses' role beliefs. Nurses' role beliefs have implications for practice and policy (Morse & Field, 2002), as do nurses' own fears of mortality (Haavardsholm & Naden, 2009). Specifically, if nurses believe their role includes providing formalized psychosocial care it can be assumed that barriers are organizational barriers whose solutions ultimately lay somewhere within the medical and nursing administrative hierarchy; nurses' energies would subsequently face that direction. Alternatively, if nurses believe their role does not include providing psychosocial care beyond comfort care, nurses may not provide formalized psychosocial care. Inadequate and fragmented at best, psychosocial care would remain as is, and PD outcomes would likely show no change until such time that nurse leaders and nurse educators seek solutions that address this issue in undergraduate educational curricula. Nurses' own anxiety in caring for patients who are facing a life-threatening illness could also be a potential barrier, but this anxiety would also be addressed within this same educational curricula. Logically, nurses' role beliefs have implications for patient outcomes regarding PD, the need for further substantiating research notwithstanding. Current barriers research will be clarified when nurses' role beliefs on providing formalized psychosocial care are better understood (NHMRC, 2003).

To clarify, formalized psychosocial care naturally includes comfort care but goes one step further to establish a system of care whose components include assessment, discussion, monitoring, and referral for intervention—clinical practice behaviors recommended in the clinical practice guidelines for the psychosocial care of adults with cancer. These practice guidelines were developed by the National Breast Cancer Centre and the National Cancer Control Initiative of Australia and are based on evidence from international psycho-oncology research that addressed the psychosocial needs of patients with cancer (NHMRC, 2003, p. 2). Psychosocial care, beyond comfort care, necessitates documentation and serves to ensure continuity of care including vigilance. Detection of distress would likely stand a better chance when such a system is in place. Kruijver, Garssen, Visser, and Kuiper (2006) reported that systematic assessment for psychosocial problems was associated with reduced distress over time.

This study will expand current barriers research by introducing nurses' role beliefs as another domain in barriers research, further supporting evidence for reducing all barriers to psychosocial care including positive social change initiatives aimed at improving psychosocial care for patients with cancer. This study will offer an opportunity to increase nurse self-awareness about current nursing care practice for patients with cancer and guide nurse leaders to consider practical concrete systems for formalized psychosocial care practice that addresses patient stress in cancer as well as in other serious illnesses. Significance for clinical practice includes the contribution of these findings towards establishing concrete actions towards psychosocial care. Critically, this study carries the potential to direct undergraduate educational change that ensures greater nurse involvement in psychosocial care.

## Assumptions

In this study I assumed that I was able to set aside my own biases, and that I did not influence the participants in their responses, or cause them to report socially desirable answers to my questions. This study was also guided by five other assumptions about nurses' role beliefs, all of which have implications for psychosocial distress and psychological care. First, I assumed that nurses would claim lack of consensus in definitions and understanding of what constitutes psychosocial care and some nurses would make no distinction between comfort care and psychosocial care.

Second, I assumed that most nurses would provide psychosocial care but only when hierarchical leaders implement structural change. At the nursing undergraduate level, change is seen as being in the hands of nurse educators. At the individual level, most hospital based nurses would not likely initiate change.

Third, I assumed that most nurses working outside the hospital setting are in a better position to initiate and implement change, albeit subjective.

Fourth, I assumed that nurses would not hesitate to provide psychosocial care to their patients with other serious medical conditions such as diabetes, asthma, or epilepsy, all of which can be associated with comorbid depression. Moreover, nurses would accept that being cognizant of the vulnerability associated with the patient status is a professional ethical responsibility (Gastmans, 1999). However, cancer is a life-threatening existential disease with an outcome that can remain poor despite advanced medical efforts. It is cancer's invisibility and, according to McKenzie and Crouch (2004), the subjective and objective uncertainty of cancer that renders it unique from other existential illnesses. McKenzie and Crouch (2004) stated:

> Cancer patients experience psychological isolation whereby their constant fear of recurrence and at times frank anxiety is a pervading mood capable of producing an affective state that creates dissonance between self and loved ones. Cancer patients' emotional and communication patterns are altered by their cancer experience. (McKenzie & Crouch, 2004, p.147)

Psychosocial care in cancer taxes nurses' own fears of cancer, psychological isolation, and, mortality; therefore providing psychosocial care is important. Providing psychosocial care without adequate training and organizational permission elicits extra stress in an already stressful setting. The lack of an infrastructure that would demand nurse accountability for psychosocial care in any and all patients implies some optionality or volition. Nurses do not appear to consider themselves accountable for psychosocial care (Powers, 2002; Schofield et al., 2006). The combination of a nurse's own fears of mortality and lack of accountability potentiates nurses' avoiding psychosocial care and further blurs the provider role.

Finally, I assumed that nurses would claim that psychosocial care is a natural outcome of good nursing care rather than a particular nursing care intervention. Historically, direct discussion with the patient about the patient's condition was considered outside the traditional nursing domain (Jecker & Self, 1991). This earlier approach may be evident in nurses' current role beliefs.

## Limitations

This study was limited in that it could not guarantee participants' honesty or full disclosure of their role beliefs, a possibility if nurses sensed disapproval for not providing psychosocial care. Nor could it dismiss the potential for bias given the volunteer requirements for focus groups (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007). Since discussions were conducted in English and the participant sample included some second language speakers participant language proficiency may have limited the richness of their narratives. However, this limitation was lessened by my attention and response as a moderator (Rubin & Rubin, 2005).

## Theoretical Framework

Lazarus's (1982) cognitive motivational relational theory guided my assessment of nurse self-perceptions on their role in providing psychosocial care. This theory posits that support is connected to clear communication. The cognitive motivational relational theory of emotion (Lazarus, 1982) is an extension of Lazarus's (1966) theory of psychological stress and appraisal that focused on appraisal of the stressor event; whether an individual experience psychological stress depended on how the individual cognitively appraised the event (Lazarus, 1991). These theories hold that cognitive appraisals are heavily influenced by emotions, that stress and emotions are interconnected and that their relationship provides insight into an individual's psychological state. Lazarus's (1982) cognitive motivational relational theory of emotion categorized 15 different types of emotions. In this study, I focused on existential emotions of anxiety (undoubtedly experienced by the patient and nurse) and compassion (an empathic emotion that is also related to the role of the nurse). The subsequent impact of these particular emotions on nursing practice is understood as part of the appraisal process "an emotion depends on the person environment relationship and the cognized significance of an event within that relationship" (Lazarus, 1991, p. 92). I will discuss the concepts of stress and emotions and their relevance to barriers, nurses' role beliefs, and psychosocial care in detail in chapter 2.

## Definition of Terms

*Cancer Survivors*: "survivorship is from the time of diagnosis through the balance of his or her life" and/or "living with cancer" (Twombly, 2004, p. 1414).

*Comfort Care:* is defined for the purpose of this study as those physical, medical care tasks aimed at providing patient comfort (McLlveen & Morse, 1995).

*Psychological Distress*: is defined according to Australia's National Breast Cancer Centre and National Cancer Control Initiative (NHMRC, 2003) clinical practice guidelines for the psychosocial care of adults with cancer. “Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional) social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and treatment. Distress extends along a continuum from normal feelings of vulnerability, sadness, and fears to problems that can become disabling such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (NHMRC, 2006, p.6).

*Psychosocial Care:* is defined as supporting the patients by listening to patients with empathy, asking specific questions about anxiety, depression, physical symptoms including body image and sexuality. Talking with patients about referral for interventions as needed, helping patients with referrals and monitoring psychological distress (NHMRC, 2003). Overall nursing actions are to assess, monitor, discuss and document. For this study, a distinction is made between comfort care and formalized systematic psychosocial care as defined by NHMRC (2003) guidelines

*Psychosocial Needs:* are defined according to Institute of Medicine (IOM) and cited in October 2007 report brief as, “understanding of illness, treatments, and services, coping with emotions associated with illness and treatments, managing health and illness, behavioral change to minimize disease impact, managing disruptions to work, school, and family life, and financial assistance” (p.2).

*Standard of Care*: is defined according to America’s Institute of Medicine (IOM) cited in October 2007 report/brief. Specifically, that

> All cancer care should ensure the provision of appropriate psychosocial health services by: facilitating effective communication between patients and care providers, identifying each patient's psychosocial needs, designing and implementing a plan that links the patient with needed psychosocial services, coordinates biomedical and psychosocial care, engages and supports patients in managing their illness and health, and systematically following up on, reevaluating, and adjusting plans. (IOM, 2007, p. 3)

## Summary

In this chapter, I provided a background of the historical progression of psychological distress as a clinical phenomenon, and presented the need for empirical research on nurse's role beliefs if nurses and policy makers are to effectively reduce all barriers to psychosocial care. I also included the study's purpose, the nature of the study and its research questions, significance and rationale, assumptions, limitations, and an outline of its theoretical framework. I concluded this chapter with a listing of the key terminology used in this study. Barriers to psychosocial care, the role and interaction of the nurse, and the theoretical framework used in this study will be discussed in chapter 2. In chapter 3, I will discuss methodology, in chapter 4, I will report my research findings, and in chapter 5, I will discuss my findings.

# Chapter 2; Literature Review

## Overview

Earlier research focused on structural barriers to psychosocial care that included time (Botti et al., 2006), workload (McCaughan & Parahoo, 2000), and nurse education ; Morita, et al., 2004; 2006). The purpose of this study is to identify nurses' role beliefs about providing psychosocial care and to determine whether these role beliefs are a barrier to psychosocial care. Those aims were addressed by using a qualitative design, interview method, and focus group methodology. In chapter 2 I will outline the data sources used to search the literature on psychological distress, psychosocial care, and the role of the nurse, and discuss the current literature pertaining to current structural barriers cited by nurses as obstacles to their providing psychosocial care. I will also discuss Lazarus's (1982) cognitive motivational relational theory and its plausible links to nurses' role beliefs and psychosocial care. In the summary of this literature review I will include a synthesis on nurses' role beliefs and psychosocial care.

## Data Sources

Literature used in this review was identified through English language online journals, Internet sources, and hard copy journals for pertinent references, bibliographies, textbooks, and books. The major search period from 1970s to present day was chosen to explain the historical progress of psychological distress to its ultimate recognition as a clinical phenomenon assumed under care by all health professionals. Databases were also used and included PsycARTICLES, PsycINFO, MEDline or Ovid, CINHL, and SAGEpub. Combinations of keywords that included *depression, anxiety, psychological* *stress, psychosocial, cancer, psychological distress, barriers, nurse communication, nurse perceptions,* and *emotional support* were used to reveal a wealth of international quantitative and qualitative studies and reviews that focused on the psychological support needs for persons with cancer. The terms *emotional care, emotional support, psychological support*, *psychosocial care*, and *psychosocial support*, were used interchangeably in the literature. Also this search did not locate scholarly articles that identified nurses' role beliefs about providing psychosocial care. Therefore, in this literature review I assemble and discuss what is known about barriers and the role of the nurse and psychosocial care, and I include contextual factors that can conceivably be interpreted as possible barriers to psychosocial care in their own right and make a case for possible solutions to each of these barriers suggesting the plausible linkage between current barriers, nurses' role beliefs, and psychosocial care according to Lazarus's (1982) cognitive motivational relational theory, in the absence of clear communication with respect to the provider role.

## Barriers to Psychosocial Care for Persons with Cancer

Barriers to psychosocial care include, but are not limited to, the earlier cited lack of time barrier reported by Botti et al. (2006), lack of education reported by Morita et al. (2004; 2006), and lack of patient privacy by McCaughan and Parahoo (2000), all barriers experienced by nurses caring for these patients. Poor treatment of PD and poor detection of PD were reported as interlinked (Pasquini & Biondi, 2007).

**Detection of distress.** According to the literature, detection of distress by nurses and physicians has been less than ideal. For example, to better understand nurses' detection of PD nurses were asked to predict distress in patients on a 5-point rating scale. Patients used a standardized questionnaire to self-report distress. The two ratings were not in agreement. Thirty six percent of patients rated distress, whereas only 16% of nurses accurately rated patient distress. Factors influencing detection were overt symptoms of distress including somatization (Plummer, et al., 2000). These findings matched earlier descriptive studies by Lampic, von Essen, Peterson, Larsson, and Sjoden, (1996) and McDonald et al.,(1999) designed to understand nurse recognition of PD; unless the patients were visibly upset and crying, their distress apparently went unrecognized. A comparison study between physicians and nurses regarding patient interaction reported differences in how physicians and nurses sought information from their patients during consultations. Nurses asked after the "well being" of patients with cancer but tended to overestimate social problems in their patients. Physicians tended not to seek information about psychosocial problems and focused more on medical symptoms, according to Salantera, Eriksson, Junnola, Salminen, and Lauri (2003) Oncology nurses did not distinguish between depression and suicide, and normal behaviors, nor did they assess for the risk of suicide (precise plan, method, and timing) in cancer patients who were suicidal, according to Valente (2007, p. 639). Nurse interventions remained at the level of encouraging patients to talk about emotional issues and listening to their patients but nurses should note that some persons with cancer consider suicide a reasonable response (p. 642) thus recommended that nurse assessment specifically include evaluating the risk of suicide, making psychiatric referrals, taking precautions against suicide including ensuring that methods of suicide are not available to the patient, and when patients do communicate their risk to nurses (Valente stated this is often the case), then nurses should be prepared to communicate openly with the patient assessing his or her psychosocial needs (Valente, 2007, p. 643) bearing in mind that communication did not necessarily increase the anxiety and depression some cancer patient's experience, according to Weiner and Roth (2006).

The development of supportive skills could improve detection of distress, although physicians who participated in this communication skills program intervention study showed no improvement in distress detection skills, according to Merckaert et al., (2005). Apparently, psychological distress was not related to the patient's medical status, although distress and somatization were correlated. Many patients were embarrassed at speaking about emotional concerns and perceived social stigmatization as a result of their cancer illness, according to Koller et al., (1996). Medical narratives have also been studied towards improving the detection of distress. The medical interview narratives of 116 patients revealed differences in the narratives of somatizing and nonsomatizing patients. Patients with depression and illness comorbidity clearly reported physical symptoms, but were unable to report the time and circumstances of the onset of their symptoms, according to Elderkin-Thompson, Cohen-Silver, and Waitzkin (1998) .

It was well acknowledged throughout the literature that lack of detection and accurate diagnosing of PD meant that many patients did not get the psychosocial care they need (Holland, 2002; Holland, 2007; Rodin et al., 2007; Ryan et al., 2005) primarily due to the incorrect presumption that depression in cancer is unavoidable, according to

Pasquini and Biondi (2007), although the earlier cited clinical guidelines are based on evidence to the contrary (Rodin et al., 2007).

***Behaviors that influence detection of distress.*** A number of studies focused on helping health professionals better detect distress. For example, McGuire, Booth, Elliott, and Jones (1996) reported three behaviors that apparently helped detection: use of open-ended questions, questions with a psychological focus that are designed to explore the patients feelings, and questions that asked patients directly about emotional concerns. Behaviors such as giving advice and giving reassurance can block disclosure because they fail to convey empathy and respect (Egan, 2006).

Patients' emotional cues have also been studied. Both verbal and non verbal cues could help detect PD, according to Ryan et al., (2005) who contended that it was up to clinicians to seek information from their patients about any concerns patients may have simply because patients may not openly express their concerns. Patients will, however, give emotional cues to communicate their concerns. In order to better detect patients' emotional cues, nurses were advised to use vocabulary that focused on the psychological state of the patient to talk about feelings. When nurses acknowledged patient distress, centered their conversations on the patients, allowed the patient to speak uninterrupted, and actively listened to their patients, nurses would more readily elicit patient concerns and detect psychological stress, according to Ryan et al. Contrary to expectation, such communicative behaviors also lessened consultation time and nurse anxiety. Nurses acknowledged the likelihood that oncology patients would have increased distress at certain times throughout their cancer treatment, most notably before and after chemotherapy and also argued that because most patients did not verbally express their emotional concerns, they tended to "intuitively assess" for distress by observing the patents' nonverbal communication, rather than asking patients directly and only one of these nurse participants made a mental health referral, according to Arantzamendi and Kearney (2004, p. 27). According to McCutcheon and Pincombe (2001), (who explored the strengths and limitations of intuitive assessment in a large Australian study using the Delphi survey technique with 262 nurses in focus groups) intuition in nursing has its limitations. Intuition was considered a valuable component of nursing but there was a noticeable lack of attention, including action, to what nurses do when nurse intuition is mistaken. In other words, nurse intuition has its place in nursing as an insightful method of reasoning (Effken, 2007; Marck, 1990; Rosanoff, 1999), but intuition alone cannot be a reliable method for detecting distress because intuition cannot be systematic. According to Purkis and Bjornsdottir (2006), detection of psychological distress must also be based on knowledge. The limitations of relying on the patient to initiate his or her psychological concerns were further evidenced by the findings that only one in four patients self-disclosed their distress and patients' emotional cues, such as hinting about concerns, and these concerns often went unnoticed by nurses (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). Detection of PD can be improved when nurses are alert for and pay greater attention to cues about worries implicit within patient conversations. Patients were more likely to verbally express their emotional concerns when nurses explored patients' emotional cues, according to Uitterhoeve et al., (2008). These findings substantiated earlier findings by Del Piccolo, Saltine, Zimmermann, and Dunn (2000), who reported that some patients who experienced psychological distress gave verbal emotional cues that were psychologically focused, while other distressed patients gave verbal behavior cues that focused on social aspects or events. Both foci were clues to PD in patients with cancer so further exploration, including asking patients directly about their feelings was seen as an essential component in successful detection for distress.

**Screening for psychological distress.** Although routine screening has yet to become standard practice, screening for distress during annual checkup visits was shown to be effective in detecting distress in cancer survivors. According to Recklitis, O'Leary and Diller (2003), one third of cancer survivors reported PD levels that included suicidal ideation. Routine screening improved detection rates of distress and has been highly recommended at different stages (Carlson & Bultz, 2003). Holland and Bultz (2006) authored a simple instrument: the Distress Thermometer a visual scale of 0 ("no distress") to 11 ("extreme distress"). The Distress Thermometer measures anxiety and ideally used in combination with a problem list to seek intensity and nature of the stress. Psycho-oncologists Bultz and Holland (2006) advocated for routine screening along the lines of checking other vital signs recommending that PD be acknowledged as the so called "sixth vital sign" (Bultz & Carlson, 2007). However, routine screening for PD would also require that nurses remain aware of the personality and cultural differences that may bias screening, such as the tendency in some cultures for patients to speak only with family members about emotional concerns (Liu, Mok, & Wong, 2005) and the inherent limitations of cross sectional self report-screenings per se, namely false-positives or false-negatives (Gilbody, Sheldon, & Wessley, 2006).

Barclay and Vega (2005) reported the Distress Thermometer (DT) with a cut-off score of 4 is as effective in detecting distress as the longer instruments 14-item Hospital Anxiety and Depression Scale (HADS)(Zigmond & Snaith, 1983), and the 18-item Brief Symptom Inventory (BSI-18) (Zabora et al., 2001), and takes less time for the patient and clinician. Other instruments include the Beck Depression Inventory (BDI) (Beck, 1961), and Center for Epidemiological Studies in Depression (CES-D) Scale, (Radloff, 1977), and modified version of DSM-IV criteria, excluding anorexia and fatigue, have also been used for measuring major depressive disorders in patients with cancer (Crespi, Ganz, Petersen, Castillo, & Caan, 2008; Pasquini & Biondi, 2007). Screening for distress would be considered helpful only when follow-up recommendations and referrals to mental health professionals become routine practice, according to Jacobsen (2007).

**Nurse patient interaction.** The philosophy of nursing as a discipline and nurse-patient relationship has been well researched. For example, nursing theorist Martinsen (1943) defined caring as the fundamental value of nursing and noted that caring involves more than one person, is practical, and learned. Martinsen also argued that caring is moral because caring requires nurses' understanding of a patient's situation and personal resources (Alvsvag, 2006). The nurse-patient relationship is said to define the nursing profession wherein the nurse patient relationship is considered an interactive relationship built on caring in the areas of person, health, and environment and maintained by nurse competency (Gamez, 2009), and Roy (2006) stated that nurses help "promote adaptive abilities and to enhance environmental interactions" in their patients (p. 362). Promoting adaptive abilities implies that nurses must also help patients manage their stress and adapt to their illness, as part of their professional role. Benner (2006) stated, “caring is primary because caring sets up the possibility of giving and receiving help” (p. 150). In a concept analysis on trust Bell and Duffy (2009) cited trust as the basic component of the nurse-patient relationship and define trust as “the optimistic acceptance of a vulnerable situation, following a careful assessment in which the truster believes that the trustee has his or her interests as paramount” (p. 50). The attributes of trust include the “expectations for competency, goodwill of others, fragility, and vulnerability and elements of risk” (p. 50). Within this concept analysis, Bell and Duffy contended that the patient becomes increasingly vulnerable as his or her nursing needs increase or intensify (p. 50). Trust provided the patient with hope and meaning although trust can be blocked by patient suffering because it affects a patient’s capacity to trust, according to Sacks and Nelson (2007), Nursing theorist Eriksson, emphasized the need for nurses to ensure patients’ human dignity: failure to ensure patient’s human dignity can mean that nursing care itself becomes a source of intolerable existential suffering for the patient (Lindstrom, Lindhol, & Zetterlund, 2002) and constitutes patient neglect (Arman, Rehnsfeld, Lindholm, Hamrin, & Eriksson, 2004). Nurse ethicist Gastmans (1999) claimed the nurse-patient relationship as the center and essence of nursing. According to Shaffer (2007), the nurse patient relationship has a distinct purpose and time span based on the patient’s needs. Gastmans further claimed that the caring process demanded “knowledge, communication, interpretation” of a patient’s needs as well as involvement. In authentic caring, nurses are willing to be affected by a patients’ suffering (Gastmans, 1999, p. 217). Eriksson reportedly agreed on this point and stated that ethics in nursing care required “we [nurses] see the patient with respect, confirm the patient's dignity, and are willing to sacrifice something of ourselves" (as cited in, Lindstrom, Lindhol, & Zetterlund, 2002, p. 196).

Trust and caring appeared as the core of the nurse patient interaction. Cancer patients themselves claimed that the "good nurse" can make a difference to patient care, according to Rchaida, Dierckx de Casterle, DeBlaeser, and Gastmans (2009) who substantiated earlier research findings that good nursing care can influence patients' coping skills and subsequent levels of PD (Latham,1996). Rchaida et al., reported the good nurse, according to patients' experiences, displayed certain characteristics subsequently categorized as (a) attitudes and (b) knowledge and skills. When nurses helped patients find positive meanings, instilled hope, provided encouragement and reassurance, were honest, kind, warm, used humor, were gentle and sensitive, and well mannered, patients' could feel respected and less nervous about exposing their vulnerability. Knowledge and skills of the good nurse included experience and competence. The good nurse acted with purpose, was able to provide information and explanations about the cancer treatment, provide physical comfort, was available for the patient and prepared to communicate with the patient. These characteristics allowed cancer patients' to feel their dignity was confirmed. Patients felt safer and less anxious about their cancer and more able to trust the nurse. Findings by Rush and Cook (2006) reported both patients and nurses cited communication as a characteristic of the good nurse. Some of these patients reported that not all nurses appeared willing to communicate.

Nurse patient interaction and communication is a major component of the nurse-patient relationship, according to Gamez (2009)  Nurse patient communication was also a topic of many studies found in the literature search. For example, Wilkinson (1991) cited four styles of verbal communication behaviors used by a sample of nurses caring for cancer patients. These behaviors were categorized as facilitating, ignoring, informing, and mixing (p. 681); verbal behaviors that blocked or facilitated communication. Facilitating implied encouraging patients to express their worries, yet Wilkinson found that some nurses' verbal facilitative behaviors were at the lowest level when patients were experiencing high levels of stress. Nurses who blocked communication may be protecting themselves against high levels of anxiety, or may be less interested in the quality of their nursing care (Wilkinson, 1991, p. 686). In other nurses poor facilitating could be due to the possibility that nurses themselves believed they had to know and provide a solution in order to relieve the patient of his or her stress (Towers & Berry, 2007). Both McCabe (2004) and Shattell (2004) claimed that nurse education was a potential barrier to effective communication because the nurses' own fear about death predicted their verbal communication behaviors and subsequently blocked patients from speaking about their concerns. McCabe further stated that nurse-patient interaction and communication skills training interventions did not necessarily lead to improvement in communication skills. Nurses were oftentimes authoritative, and the so-called "difficult" patients received less supportive care from nurses. When nurses appeared hurried and unapproachable, patients hesitated to communicate their emotional concerns (McCabe, 2004). According to Wilkinson (1991) predictors of facilitating communication included the ward on which the nurse worked, degree of support from nurse superiors, nurse's own stress about communicating with the patient with cancer, and whether or not the nurse had taken graduate or further education.

Nurse patient communication is considered "good" when it is centered on checking with and supporting the patient. Organizational structures that emphasized nursing tasks resulted in less than ideal nurse patient interaction because rather than checking directly with the patient, nurses simply assumed they understood patient needs, according to McCabe (2004). The positive effects of communication skills training were often blocked by a number of social barriers that included workplace policies, biomedical model, collegial social support, lack of education, plus an emphasis on mechanistic over relational communication, according to Chant, Jenkinson, Randle, and Russell (2002). Chant et al., cited an earlier article authored by Hartrick (1997) in which Hartrick had stated that therapeutic communication should be concerned with developing the relationship rather than communication strategies. Chant et al. further explained that mechanistic communication was a communication strategy that was aimed at problem solving whereas relational communication was aimed at developing caring relations between nurse and patient (Chant et al., 2002). Specific communication skills promoted in communication education courses for nurses include "mechanistic communication" such as "clarification, open-ended questions, listening, self-disclosure, empathy, attending, confrontation and immediacy" (Hartrick, 1997, p. 15). Relational capacities include "authenticity, initiative, mutuality and synchrony, honoring complexities and ambiguity, and intentionality" (p. 526) and Hartrick further stated that relational communication encouraged nurses to avoid preoccupation with “needing to say the right thing” (p. 527) as opposed to relational communication that emphasizes “being actively concerned for and about others” (p. 527). An overemphasis on ”skills” at the expense of developing one’s relational capacities could paradoxically result in patients withholding emotional concerns.

Nurses needing to manage their own negative emotions can potentially have an adverse effect on their nurse patient communication, as well as nurse physician patient communication, because nurses will avoid conversations with a psychological focus, according to Kennedy, Sheldon, Barrett, and Ellington (2006) and in order to manage their own distressing emotions, nurses may avoid authentic, relational communication, according to Chant et al., (2002). Nevertheless, improved nurse communication skills can also result in improved job satisfaction (McGilton, Irwin Robinson, Boscart, &Spanjevic, 2006). Such improvement in communication skills and job-satisfaction was an important finding since it may follow that nurses would feel more confident to explore patient concerns following skills training intervention. This assumes that communication skills training includes checking with the patient directly, appropriate exploring for emotional concerns, and focusing on the emotional elements of the patient’s statements, as cited in the earlier findings by Ryan et al., (2005).

Researchers Uitterhoeve et al., (2008) explored nurse-patient communication in their observation and interview design study that measured three levels of emotional cues. Level one was described as the patient hinting about a worry. Level two, the patient uses language that makes mention of a worry, and at level three the patient expresses worry and anxiety, verbally and behaviorally, for example, openly crying. Nurses' responses to patients' emotional cues were classed as *form or function* the latter explained whether the nurse explored the cue or used distancing behaviors, namely advice giving and reassurance. Form referred to the style of questions, dichotomous, or open questions that required discussion and exploration with the patient. In this sample of nurses, half of patients' cues were blocked by nurses' failure to explore. Of the other half, 33 percent of cues were explored and 17 percent acknowledged. The most used communication blocking strategy was, changing the topic of conversation. Some nurses acknowledged patient concerns but did not explore patent's emotional cue. Open-directive questions were only effective when used in response to an emotional cue. Responding to a cue increased the likelihood of disclosure of a patient's emotional concerns according to Uitterhoeve et al., (2008). The sequence outlined by Uitterhoeve et al., is noteworthy. First, using open-direct questions without an emotional cue could likely block disclosure of patient's worries or concerns. Moreover, in the absence of an emotional cue open-directive questions may aggravate anxiety and result in further isolating the patient. The importance of the earlier cited mechanistic versus relational communication was evidenced in these findings to serve as a helpful reminder for effective detection of distress and its follow up psychosocial care, as was the importance of observing for emotional cues.

**Nurse perceptions of psychosocial care.** Any precise meaning of psychosocial care appeared lacking within the literature. Community nurses in the UK reported the lack of clear definition of psychosocial support and an unclear sense of appropriateness and uncertainty when compared to physical care and further claimed their lack of skills and lack of confidence in providing support to patients in palliative care. They considered psychosocial care complex, and its boundaries unhelpfully blurred, according to Griffith et al., (2007) Further, Henderson (2001) claimed that nursing education did too little to prepare nurses for the emotional aspects of nursing, a factor highly criticized by nurses in a Canadian qualitative study on caring work cited in Henderson's article on *emotional labor* in nursing. Nurses expressed "profound disappointment" (p. 134) at nurse educators over this perceived void in nursing education. Nurses recognized the need for emotion focused conversations with their patients and expressed concerns about their perceived lack of communication skills and training which they considered essential for nurses in their daily care for all patients, according to Kennedy, Barrett, and Ellington (2006)

Seminal work on social system defenses by Menzies (1959) claimed that the "demand for rituals and insistence on the task" focus in nursing are some of the social defense mechanisms constructed by hospital systems against the inevitable anxiety inherent in caring for ill and dying patients (Menzies, 1959, p. 291). It is interesting to think about how the lack of clarity on nurse role and expectations might play into Menzies's findings. Specifically, and based on Menzies argument here, education on psychological work and communication and the role of the nurse might mean nurses would experience less anxiety because they will have learned how to better provide psychosocial care to their patients.

Motyka, Motyka, and Wsolek (1997) listed seven behaviors defined by nurses as psychosocial support; “reassuring, collecting information, offering explanation, advice giving, referring out, demonstrating warmth and friendliness, demonstrating empathy, and understanding”. Intellectually, these nurses valued the importance of clarification and exploration of patients’ feelings, yet many of these nurses took the “authoritative” approach (p. 912). An authoritative approach can interfere with cultivating a nurse patient relationship that may invite the distressed patient from expressing his or her emotional concerns (Artinian, 1995). Lussier and Richard (2007) stated that empathic listening by its definition as a “psychological strategy” allows one to “reconstruct a patients’ feelings”. Empathic listening can only be considered effective when the patient recognizes and subsequently acknowledges such reconstruction on the part of the other. Lussier and Richard further stated that one of the first steps in reconstructing a patient’s feelings is to “be calm and adopt a neutral stance” because such an approach will allow one to begin with an open mind to imagine, identify, and proceed (Lussier & Richard, 2007, para. 3). Motyka, Motyka, and Wsolek’s above finding may be connected to Henderson’s (2001) earlier point that nurses feel unprepared for the emotional work involved in nursing, or alternatively feel rushed and without sufficient time (McCaughan & Parahoo, 2000). Marck (1990) argued for the distinction between interactional behaviors and “therapeutic reciprocity” which was defined as “a mutual, collaborative, probabilistic, instructive, and empowering exchange of feelings, thoughts, and behaviors between nurse and client for the purpose of enhancing the human outcomes of the relationship for all parties concerned” (p. 57). Marck further claimed that reciprocity is “equal and unidirectional” (p. 53) and commences with nurses being willing to engage in feelings that have come about as a result of the illness situation where humanity of both the patient and nurse is shared (Marck, 1990, p. 53). Therapeutic reciprocity is arguably a highly important component of psychosocial care, if not its defining component, and sets the approach to psychosocial care.

Several studies were located that addressed nurses’ documentation and record keeping. Summarily, nurses’ documentation indicated a lack of any record of comprehensive care. Nurses did not record observations of patient’s emotional state in such a way as to be helpful for diagnosing and monitoring and records tended to focus on the physical needs of the patient and their immediate outcomes. Moreover, nurses records tended to reflect nurses’ perception of patient needs rather than patients’ actual needs and were centered more on the nurses’ needs rather than those of the patients (Friberg, Bergh, A-L., & Lepp, 2006; Gillan, 1994; Karkkainen, Bondas, & Eriksson, 2005; Taylor, 2003; Voyer, Cole, St-Jacques, & Laplante, 2008). This was a significant finding because according to Ernstmann et al., (2009) it was the patient’s subjective perception of their own emotional functioning that ultimately determined their psychosocial support care needs, meaning that patient discussion is the only way nurses can be sure here, patients declining disclosure notwithstanding. When nurses fail to discuss patient needs directly with the patient they likely miss the opportunity to help address those needs and further run the risk of perpetuating their patient’s emotional distress. Voyer et al., studied nurses’ recordings of 226 patients with delirium and reported that only one third of the records contained any notes about their patients’ symptoms of delirium. Friberg and colleagues used 35 patient records and 206 days of nurse recordings for their findings that reflected patients' educational needs were also poorly addressed. Karkkainen and colleagues noted above conducted a metasynthesis of 14 qualitative studies and reported that nurse records tended to reflect the needs of the organization or institution. It would seem that either these nurses did not observe or assess the emotional state and concerns of their patients, or they did observe and assess, but their records did not reflect their actual nursing care. A third option could be that these nurses did observe and did assess but took no further action. It seemed that only when a patient was overtly distressed, crying and visibly upset, did the record reflect nursing action, at best. Ultimately, this approach blocked psychosocial care, however unwittingly. These studies were compelling in that they bring into question nurse accountability for psychosocial care. Lack of accountability for psychosocial care implies that providing psychosocial care is optional for the nurse. Nurses are certainly accountable for their patients' physical care and wellbeing but accountability for psychosocial care appears to remain unclear, at best. These studies further point to the lack of clear expectations for nurses providing systematic psychosocial care, the lack of role clarity, and the importance of its clarification. Some may cite the adage "nursing is caring"; providing psychosocial care clearly lies within nurse role. Their argument is not contested. To reiterate, the focus here is on specific, formalized, systematic, psychosocial care. Documentation would be one routine component of psychosocial care that allows for continuity of care. Theoretically, it would follow that distress becomes more readily identified as a result. The clinical practice guidelines also appear to hold this expectation. In considering the philosophy of nursing in its relation to psychosocial care, Gastmans (1999) made the argument that nurses too often became side-tracked by the technicalities of the nursing role, even though it is human care that is the role and responsibility of the nurse. Gastmans further claimed that nurse identity comes from both the nursing tasks performed and the “attitude” to caring. Gastmans emphasized that the attitude should prevail and as nurses we must understand the “moral significance” of our actions. Care must center on the person and his or her needs. The ethical responsibility of the nurse is to accept the patient’s vulnerability with respect, especially given that “patient vulnerability can invite neglect” (Gastmans, 1999, p. 218). Attitude to caring can be expected to develop from experience and education, as well as the surrounding organizational infrastructures. Education about the role and responsibility of the nurse with respect to formalized psychosocial care can surely better promote the development of Gastmans ethical responsibilities within the nurse’s professional role.

**Patient perceptions of psychosocial care**. According to Navon (1999) some patients will view their cancer diagnosis differently. For example, some patients may see their cancer as either predestined, within one’s control, or as normal suffering, depending on their personality and culture. Navon further stated that because social norms influence emotional expression, this would include whether patients choose to disclose their worries about their illness. The role of cultural differences was further reiterated in a qualitative study by Liu, Mok, and Wong (2005) with Chinese cancer patients who reported differences in their expectations regarding psychosocial care. These patients were of the opinion that caring behaviors of the nurse was one potential source of support. Fellow patients were another source. However, family members were the major sources of support for these patients. Powell (2006) further discussed the role of the family in her essay on medicine and culture citing Fetters's (1989) concept of "family autonomy." Powell's essay included an explanation of the Japanese use of *isshin denshin* defined as unspoken communication. Unspoken communication is considered to protect the patient. Family members may choose to use this supportive approach throughout the entire illness experience including diagnosis disclosure and prognosis (Powell, 2006, para. 23). Also, some patients may avoid disclosing their emotional concerns because they fear social stigma associated with their cancer illness and its debilitating effects (Im, 2000). Reidpath, Chan, Gifford, and Allotey (2005) held that nurses should wherever possible help patients in their efforts to maintain their capabilities for social functioning; it is through social functioning that we develop our "reciprocal exchange and social value". Reducing one's social value results in stigmatization (Reidpath et al., 2005, p. 483). Shih (2004) claimed that stigma in mental illness can be a chronic stressor because patients subsequently overly question their own capabilities to be self sufficient, negatively impacts identity, results in reduced social support, isolation, and perceived alienation. Shih further claimed that patients would likely benefit from education about stress and coping to help develop resilience against the unwanted affects of stigma. According to Shattell (2004), patients wanted for nurses to be authentic and willing to take the time to talk to them. Indeed, patients' perceptions of caring included nurses using their skills to monitor and follow up on patient needs (Larson, 1986).

According to McCabe (2004), some patients may simply prefer not to initiate conversations about their psychosocial concerns hoping rather that the health professionals might take the first step. This preference appears to be quite prevalent according to a report published by professionals at the Institute of Medicine (IOM) who stated that patients were disappointed that their health care professionals did not pay more attention to the psychosocial needs of their patients, including providing education and referrals to health services (IOM, 2007). The IOM subsequently compiled a systematic framework for use by all health professionals that recommended: "Identify psychosocial needs, refer and connect patients with appropriate services, support patients and their families in managing the illness, coordinate medical and psychosocial care, and follow up and monitor" (IOM, 2007, p. 2). Using this framework makes for humane dialogue with patients because it focuses on medical professionals collaborating with patients to offer concrete help with the practical components involved in meeting their psychosocial needs. Patients would likely find such an approach more acceptable and respectful as well. Use of a good framework would be less time consuming because in theory it offers a systematic approach to holistic follow up.

**Lack of time, skills, and education.** Nurses cited time and workload (Botti, et al., 2006), and education (McCaughan & Parahoo, 2000; Morita et al., 2006)) as barriers to psychosocial care. Botti et al., (2006) conducted an exploratory design using two focus groups of 15 nurses. Interview data were analyzed according to themes that included workload, time to talk, trust, skills and education, emotional involvement. Since nurses did not have collegial discussions about patients, it was stated that nurses needed to be better supported if they are expected to provide psychosocial care (Botti et al., 2006). Nurses' emotional involvement was one theme in a qualitative study with nurses in Canada conducted by Henderson (2001) who reported that making efforts to balance emotional involvement was important but emotional involvement was also valued by nurses as a "requirement of excellence in nursing" (p. 133). According to Bolton (2000), nurses claimed that even though emotional engagement often elicited anxiety, nursing was satisfying because of the emotional engagement. McVicar (2003) reported that workload and decision-making were cited as sources of stress for nurses in the workplace yet the emotional aspects of caring were not cited as sources of stress for these nurses. Ekedahl and Wengstrom (2006) reported that although cancer nurses did experience stress they also found ways to cope that included establishing boundaries, venting with colleagues, using humor and, seeking collegial support. Dysfunctional coping was associated with lack of support and lack of role clarity. These nurses defined dysfunctional coping as being over involved in their work "giving more than 100% at work" (p. 133) and, not making professional boundaries. Cohen and Erickson (2006) stated that nurses reported moral distress because they are unable to provide the care they believe cancer patients should receive. Morita et al., (2006) stated that knowledge deficits and lack of collaboration were cited as impediments to care by nurses. Forty percent of these nurses did not adhere to clinical guidelines. However, improvements were noted following six one-hour lectures and daily team activities for one year wherein these nurses reported increased confidence, knowledge, and collaboration.

Nurses’ concern about their education deficits with respect to psychosocial care was frequently cited in the literature. According to McCaughan and Parahoo (2000) out of a total of 23 further education topics, dealing with psychosocial support for patients with cancer was the highest ranked request for education in cancer nurses working in the hospital setting. This literature review located a free online series of lectures offered by the combined efforts of the International Psycho Oncology Society and the American Psycho Oncology Society (IPOS; APOS) that included psychological distress and its management, ethical issues, detecting distress, education and support for families (APOS). Further, a continuing education professional development article for nurses published in a nursing professional journal offered a course that included activities on providing psychosocial support (Towers & Berry, 2007). Several salient factors taken from the Towers and Berry article include: Nurses who cited time as a barrier could overcome this problem when they concurrently with other nursing duties talk with patients about how they are coping; assessing psychosocial needs. Structuring in a few extra minutes daily will make the difference to nurse and patients, according to the these researchers. Nurses might withhold psychosocial care because they believe they need to solve every problem. This approach per se, is problematic; nurses do not have to have all the solutions; nurses should also learn to accept silence. Other recommendations made by Towers and Berry were for nurses to observe for patient’s emotional cues, explore incongruent behaviors, and only after rapport is developed, ask the patients directly about distress and their ideas about referrals for psychological care, if any incongruence cannot be explained. Finally, structural barriers are real and genuine but nurses need to be sure that we are not hesitating to engage because we nurses find it emotionally distressing (Towers & Berry, 2007). These courses on psychosocial care were easily accessible, credible, economical or at no cost, and without jargon and subsequently significant because cost and poor accessibility to research were two reasons why nurses did not make use of current research findings (McCaughan, Thompson, Cullum, Sheldon and Thompson, 2002). Individual nurses can become better educated about psychological distress in patients with cancer based on these articles and courses outlined above. However, it is accepted that implementing the findings into daily practice requires further imagination, and high levels of support.

**Limitations to nurses' autonomy.** Researchers Coombs and Ersser (2003) claimed that nursing responsibilities have increased but nurse authority has not paralleled this. Although the sample in Coombs and Ersser's study involved intensive care nurses it is reasonable to assume that their findings are useful for understanding nursing authority in cancer care settings, given the complexity of care in both areas. Coombs and Ersser reported that nursing knowledge was invariably seconded to medical knowledge. Medical staff acknowledged nursing knowledge intellectually, but not practically. Although these nurses were well placed to monitor patients, it was the physicians who controlled the clinical decisions. These nurses hesitated to give their opinions about the patient's situation to medical staff, and reported lack of confidence. One physician did express lack of appreciation for a nurse's response that "I'm only a nurse." To the contrary Gordon (2005) argued that nurse hesitancy to give unrequested opinions to medical staff is a manifestation of the "invisible nurse" (p. 13) a phenomenon said to be created by existing medical structures designed to perpetuate medical decision-making through so called “medical hegemony” as expressed by Coombs and Ersser (2003, p. 245).

With respect to using the earlier cited clinical guidelines for psychosocial care Mead (2000) examined literature pertaining to use of these guidelines. Clinical guidelines were reportedly based on best evidence but some practitioners did not use the guidelines, especially when they were not confident in the evidence. Nevertheless, given the current medical hierarchy unless physicians used the guidelines nurses would be less likely to initiate them (Coombs & Ersser, 2003). It is unclear how nurses, or any health-care professional for that matter, would answer the claim by Wysocki and Bookbinder (2006) that clinical guidelines are an evidence based tool that health professionals can utilize to fulfill the assumed social contract for ideal health care. However, hierarchical structures meant nurses recommended rather than decided (MacNeela, Scott, Treacy, & Hyde, 2007). Although this was a sample of mental health nurses it is nevertheless reasonable to assume the implications of their findings will transfer to all nurses based on its connection of psychological work in psychosocial care. Despite the reasonable expectation that mental health nurses would surely hold some decision-making authorities concerning psychiatric referrals, these nurses stated their nursing decisions for psychiatric referrals required endorsement by the medical staff. Hierarchical structures meant that even specialist nurses lacked sufficient empowerment. MacNeela et al., (2007) further stated that perceived disempowerment could extend to nurses not taking on the role of providing psychosocial care. The importance of clarifying nurses’ role beliefs was made obvious by these articles, as were the subtle but powerful social barriers that also currently play a role in obstructing psychosocial care.

The influence of nurse leaders on barriers to psychosocial care was also addressed in the literature. Nurse's self-efficacy was influenced by nurse leaders self-efficacy. Structural empowerment contributed to professional practice through self-efficacy, but only when nurse leadership was strong, according to Manojlovich (2005) Ellefsen and Hamilton (2000) made the distinction between formal and informal structures that empower: Power refers to authority and to *i*nfluence within group relationships. According to Kuokkanen and Leino-Kilpi (2000) empowerment is developmental and influenced by "positive self-identity, capacity for awareness and reflection about one's environment and, capacity for discourse" (p. 239). Structural empowerment has resulted in psychological empowerment to subsequently influence job satisfaction in a positive way (Spence, Laschinger, Finegan, Shamian & Wilk, 2001). These findings could imply that some nurses would strive to overcome many barriers to integrated care when supported by nurse leaders, for example. That most nurses lack necessary authority is not in question but nurses making use of informal power structures to initiate discourse towards systematic psychosocial care is nevertheless considered feasible, realistic and worthy of serious consideration. A place for combining the energies of nurse educators and veteran nurses has also been made clear by these studies. Their respective experiences and knowledge could also help establish concrete frameworks for implementing into daily practice. According to Wysocki and Bookbinder (2005) practice change has a greater change for success when it can be initiated informally, at the individual level, and with few economic demands.

## Biomedical Model

In his seminal works on the biopsychosocial model Engel (1977) argued that we will create more problems if we do not make the shift that naturally includes social, behavioral, and psychological components simply because the biomedical model is reductionist. Engel further argued that the biomedical model may have been congruent with the social norms and medical circumstances in the 17th century but modern scientific knowledge has since evidenced that social, psychological and biological domains interact to subsequently influence the course of some illnesses and disease. Therefore, all three domains should be incorporated into holistic care. Engel claimed that the patient physician consultation per se is to be valued as a method of data collecting because ideally it includes the patient perspective. Engel further argued that in the medical consultation the dialogue per se offers the data. This dialogue can be claimed as a legitimate and scientific approach (Engel, 1977, 1980, 1997).

The biopsychosocial model is considered a framework for a preferred way of thinking about illness and disease, and should be used to guide the approach to treatment because it offers an essential broader base (McLaren, 1998; Russo & Budd, 1987; Stam, 2000). Piko and Stempsey (2002) contended that single causation as implied by the current medical model oversimplifies any illness and disease. Richter (1999) discussed the arguments against Engel’s biopsychosocial framework, in particular the argument that the biopsychosocial model oversimplifies the interaction between the different domains and fails to guide decision-making. Richter counter argued that the onus rests on medical systems of care that either support or impair the biopsychosocial framework. However, Mitchell and Bournes (2000) contended that claiming systems are at fault is a circular argument and that patient vulnerabilities should be recognized as the inevitable result of biomedical nursing that simply disallows authentic holistic care. A method that may assist nurses towards more comprehensive care and therefore worthy of consideration is the patient evaluation grid (PEG) originally designed for patients in psychiatric care and formulated by Leigh, Feinstein, and Reiser (1980). Leigh et al. claimed that the PEG helps the clinician organize and prioritize patient data along the lines of biological, psychological, and social factors. As such, some aspects of the PEG may be transferable to nursing care plans. The nurse could collect clinical information specific to the present problem, on three domains biological (physical state, laboratory data, diagnosis, treatment) psychological or behavioral (psychological state and anxiety including questions such as "what does the patient think about the symptoms?") and environmental or social relations (availability of social support). Leigh et al., further stated that these three domains were designed to address current, recent, and background contexts and subsequent clinical decision making best guided by the following steps: First, list the factors that appear most important for the patient who is suffering, within the disease, within meanings of the illness, and within medical care system. Second, list the major limitations within the proposed interventions and then prioritize the patient's care needs. The recommendations underlying the biopsychosocial model, the PEG, and earlier cited framework (IOM) all appear to encourage a holistic approach to care for medical patients and psychological distress.

Swisher (1980) argued for the *m*ultidisciplinary model rather than the interdisciplinary model claiming the former assumes that disciplines originate as a single unit from which individual disciplines branch out. Health psychologists have used the term *transdisciplinary* (Suls & Rothman, 2004) implying links and cooperation with other disciplines. Swisher contended that the interdisciplinary model assumes disciplines are single units which may or may not combine to provide ideal health care. Coombs and Ersser (2003) argued that frameworks that promote the multidisciplinary model could theoretically help ensure holistic care, decision-making problems notwithstanding. The term interdisciplinary may set the philosophical tone for such an approach and decision-making priorities and processes in the interdisciplinary model unless are contingent upon all parties agreeing with the interdisciplinary approach. Given that Engel's framework promotes the medical encounter as a source of data (Engel, 1997) the biopsychosocial framework could potentially elicit information about coping strategies and be an ideal guide for understanding the cancer experience. Beresford, Alfers, Magnum, Clapp, and Martin (2006) conducted a five-year longitudinal study that focused on cumulative survival probability in patients with late stage cancer and reported that patients who used adaptive coping styles experienced less distress and increased survival and patients who used dysfunctional styles of coping experienced higher levels of depression and lower survival. Both the IOM recommendations and the clinical guidelines for psychosocial care specifically mention the importance of integrated care. Medical interviews address coping behaviors, the availability of social support, and any physical symptoms experienced by the patient, thus reflect the principles of Engel's biopsychosocial model (Thomas & Bultz, 2008).

An earlier article by Sadler and Hulgus (1992) on the biopsychosocial model offered a helpful way of thinking about the clinical encounter could lead to increased nurse confidence in providing formalized psychosocial care simply because it lays out a scaffolding for holistic care. Sadler and Hulgus designed the t*hree faces model*, a structure for clinical decision-making. Clinical decision making was considered problematic by earlier critics of the biopsychosocial model (Dowrick, May, Richardson, & Bundred, 1996). Sadler and Hulgus contended that clinical decisions should address "epistemic, ethical, and pragmatic components of medicine " (p. 1317); interdependent "faces" that should be considered when making clinical decisions. Sadler and Hulgus explained that the epistemic dimension refers to the clinical medical knowledge, ethics involves the patient's beliefs and attitudes, and pragmatics involves long-term thinking about possible problems that could come about as a result of any epistemic decision made by the health professional. First, define the problem, second, consider necessary actions and their respective consequences, and third, consider values and implications of those actions (Sadler & Hulgus, 1992). While the biomedical model may dominate at this time, the articles cited above offered ways that nurses might circumvent some of the problems associated with the biomedical model. Nurses need clear guidance on the role of providing psychosocial care beforehand however.

## Theoretical Framework

Based on the literature review and this researcher's nursing experience, providing psychosocial care can be understood within Lazarus's (1982) cognitive motivational relational theory of emotion. Lazarus holds that appraisal is a process that includes cognition and emotions; emotions are consequences of our appraisals. Depending on the appraised significance of the event (Lazarus refers to as the relational meaning in the person environment relationship), a particular emotion will result to subsequently offer an explanation for thoughts and behavior. Lazarus argued that "thought is a necessary condition of emotion" (Lazarus, 1982, p. 1019). Because stress and emotions are intertwined, each emotion carries a *core relational meaning*. The core relational meaning of anxiety is threat and specific to cancer, the "threat of nonbeing". The core relational meaning of compassion is empathy (Lazarus, 1982, p. 235; Lazarus, 1984; Lazarus, 1991; Lazarus, 2006). The diagnosis of cancer brings anxiety because it threatens life and identity. The nurse's clinical practice will reflect the nurse's emotions and appraisals. Possible scenarios are as follows:

1. The nurse holds the personal belief that the role of the nurse does include providing psychosocial care. The nurse's goal is for holistic care, but organizational barriers, and uncertainty about the provider role and its processes, thwart the goal. The nurse experiences guilt and stress; core relational meaning of guilt is moral lapse. In citing organizational barriers the nurse's reappraisals will rationalize withholding psychosocial care.

2. The nurse holds the personal belief that the role of the nurse does include

providing psychosocial care. The nurse's goal is for holistic care. The nurse's own fear of death comes in response to the patient's anxiety. The nurse may block emotional cues and cite organizational barriers, and subsequently not provide psychosocial care.

3. The nurse holds the personal belief that psychosocial care is outside the nurse's role. No goal has been thwarted. No stress is likely. The response to the patient's anxiety will be empathic. The nurse's reappraisals will be intellectualized and the nurse will provide comfort care.

Earlier barriers research implied and presupposed that nurses would provide psychosocial care but for organizational barriers (Botti et al., 2006). However, according to Corner (1988) nurses focused more on tasks and blocked communication when patients seemingly experienced distress. Nurses provide psychosocial care to patients with other diagnoses (Chalco et al.,(2006) and nurses found creative ways around structural or organizational barriers in other areas of nursing with good results (Tanner & Hale, 2002). Nurses have also self-reported effective problem solving capacities (Bennett & Lowe, 2008). Some oncology nurses reported moral distress in caring for patients with cancer because they were unable to provide full and ideal care (Bennett & Lowe, 2008; Cohen & Erickson, 2006). All of these findings, including findings that nurses blocked patient's emotional cues (Chant et al., 2002; McCabe, 2004; Wilkinson, 1991) seem centered on the nature of the cancer diagnosis; existential emotions associated with cancer likely play a role in whether some nurses provide or withhold psychosocial care, as things currently stand. This avoidance is plausibly due to the lack of clarity about provider role expectations despite the expectations implied and recommended in the clinical guidelines. Compellingly, nurses did not document their psychosocial care (Friberg, Bergh, A-L., & Lepp, 2006; Gillan, 1994; Karkkainen, Bondas, & Eriksson, 2005; Taylor, 2003) so it follows that nurses need clarification here.

Qualitative researchers hold that theoretical perspectives are not always directed towards application. Rather, theory offers possibilities for meaningful "scrutiny"; we seek to understand meanings, and the logic of the participants (Charmaz, 2004, p. 985). As it relates to this present study, Lazarus's (1982) theory of emotions and stress provides insight into current clinical practice. Clarify the provider role, give necessary education, skills, and support, and nurses working to circumvent organizational barriers will naturally follow. Providing psychosocial care to patients with cancer will always elicit existential emotions. However, when nurses are educated about psychological distress and are confident that their role does include providing psychosocial care, clinical practice would reflect that appraisal. Therapeutic reciprocity*,* being open to patient's existential emotions and stress, would ideally follow (Marck, 1990). Lazarus's theory of emotions reinforces the need to identify and determine nurse's role beliefs for the benefit of patient and nurse, in reducing current barriers to psychosocial care.

## Summary

This literature review acknowledged barriers to psychosocial care that included poor detection, nurse's patient interaction, nurse perception of psychosocial care, patient perception of psychosocial care, nurse's lack of skills/education, lack of time, nurse autonomy limitations, and the role of the biomedical model. Critically, this literature review revealed that the majority of these structural barriers invariably have alternatives that offered feasible solutions to providing psychosocial care. Structural barriers alone may not explain why nurses claimed they are unable to provide psychosocial care. Decisively, this research revealed a lack of clarity on nurse's role beliefs about providing psychosocial care; nurse's role beliefs were presumed to include the provision of formalized psychosocial care, but where do nurses stand on this point? It is possible that this lack of clarity on nurse's role beliefs has contributed to the current fragmented psychosocial care. Ultimately, structural barriers to psychosocial care discussed above have come full circle; patients still remain in need of psychosocial care and nurses are well placed to provide that care. Also decisively, nurses provided psychosocial care for other diagnoses and self reported effective problem solving skills (Bennett & Lowe, 2008; Tanner & Hale, 2002). It is a reasonable expectation that all nurses should play a greater role in providing psychosocial care but nurses need clear guidance on their role in the psychosocial care for patients with cancer. Compellingly, these structural barriers were unable to explain the paradox that currently nurses' providing psychosocial care appears primarily volitional and at the discretion of the individual nurse, regardless of nursing specialty. Volition is implied by the lack of nurse documentation of psychosocial care, and the lack of structural accountability for psychosocial care. These factors are all reasonably interpreted as plausibly linked with nurse's role beliefs about providing psychosocial care. Empirical knowledge on nurses' role beliefs is essential because role beliefs guide clinical practice; current clinical practice will likely not change nor will current barriers be changed unless role beliefs are addressed. The first step is to identify and determine whether or not those role beliefs are also barriers to care. Identification and exploration of nurses’ beliefs about providing psychosocial care is the purpose of this study and discussion of its methodology follows in chapter 3.

# Chapter 3: Research Method

## Overview

This was a qualitative descriptive design study that used the focus group method to identify nurses' role beliefs about providing psychosocial care and to determine whether these role beliefs were a barrier to psychosocial care. In seeking to identify nurses' role beliefs, the participants were asked three major research questions: (a) nurses' role beliefs about providing psychosocial care to patients with cancer, (b) whether nurses believed they should have a role in providing psychosocial care, and (c) what nurses believed it would take for nurses to take on a greater role in order that patients get the psychosocial care they needed. Nurses experienced structural barriers to providing psychosocial care but it was unclear whether nurses' role beliefs themselves could be determined as a barrier to psychosocial care. Chapter 3 is organized to address the major components of the methodology used in this study: (a) introduction and rationale for design, (b) sample and recruitment, (c) data collection, (d) data analysis and limitations, (e) ethical considerations, and (f) reflexive statement, and concludes with a brief summary.

## Introduction

The nursing discipline may carry the image that nurses provide balanced physical and emotional care but as indicated in the above literature review the reality is that physical care dominates, however well intended the nurse. Psychosocial care should not be confused with comfort care, as explained earlier; psychosocial care requires assessment, discussion, monitoring, and referral as necessary, and critically involves documentation designed to provide a pathway for integrated care (NHMRC, 2003). The clinical practice guidelines for psychological care of adults with cancer (NHMRC, 2003) carry the expectation that nurses will provide psychosocial care, yet discrepancies remain. The premise of this research was that nurses were presupposed providers of psychosocial care but nurses own perceptions of this provider role were unknown. This knowledge was necessary if the original aim for increased nurse involvement was to be realized. Regarding the epistemology pertinent to this study, exploring nurses’ role beliefs about providing psychosocial care was the purpose of this study and seen as incongruent with the ontological and epistemological parameters associated with positivist inquiry (Bloomberg & Volpe, 2008). The purpose actions were in accordance with a nonpositivist paradigm in general and the constructionist interpretive paradigm in particular; a critical theory paradigm would have focused on changing nurses’ role beliefs (Bloomberg & Volpe, 2008). The constructivist interpretive paradigm was concerned with *how* nurses talked about their role with respect to psychosocial care (Freeman, 2006), including what opinions nurses shared about the nurses’ role (Rubin & Rubin, 2005).

## Research Design and Approach

This study used the focus group design to answer the research questions. According to Wilkinson (1999), focus groups, first used in market research, have been used in psychological research since the 1990s. Focus groups hold the capacity for clarifying, sharing, and debating different perspectives (Kitzinger, 1995). Rationale for selection of this design was related to its purpose: namely, to identify nurse’s role beliefs and determine if those role beliefs were a barrier to psychosocial care. Also according to Kitzinger (1995), focus groups are an effective and useful data collection method for exploring the what, how, and why of people's knowledge. According to Morgan (1997), effective focus groups offer wide range of perspectives and generate interaction that explores how the participants feel about an issue, and include participants' personal context that can explain their particular perspective. Morgan further claimed that focus groups bring all the different personal experiences and resultant perspectives of the participants together and the resultant group interaction allows research questions to be answered (p. 45). For this study, the focus group design carried advantages over the single interview method: nurses were able to discuss their role beliefs, to explore previous research findings, and to explore a topic omitted in previous research (Macleod Clark, Maben, & Jones, 1996). Focus groups naturally elicit differences and contradictions, but these differences could also provide valuable data (Winship & Repper, 2007). Appropriate sample size and safe atmosphere in the focus group method encouraged participation and sharing of ideas and experiences to provide data depth, including its saturation (Flick, 2002; Napier & Gershenfeld, 1999; Sandelowski, 1995). The possibility that nurses might have sensed disapproval from a fellow nurse for not providing psychosocial care was cited as a limitation, both ethically as well as data credibility (Collins, Shattell, & Thomas, 2005). However, this potential obstacle to honest and free flowing discussion was addressed by providing clear explanations prior to discussions (Kitzinger, 1995). The participants are always the main speakers in the focus group design (Kidd & Parshall, 2000; Macleod, Clark, Maben, & Jones, 1996). The focus groups in this study were a group of peers. Using a group of peers to form the focus groups was seen as an advantage because all members were familiar with the nursing world context (Macleod et al., 1996). Also, the quality of focus group data is influenced by the moderator's skills for encouraging discussion while making every effort against leading or biasing the participants (Sim, 1998). Opening statements clarified expectations for valued participation and helped to set the tone for participatory interaction, ensure opportunities for fair and reasonable participation, and increase reliability (Karnielli-Miller, Strier, & Pessach, 2009; Macleod et al., 1996). Given these reasons, the focus group design was seen as the best fit for this study and in accordance with Morse's (2003) point to produce evidence that was valid, carried the potential to extend knowledge, and could be claimed as useful.

## Setting

This study took place in Japan in the month of July. Focus group discussions were held in a high school classroom chosen for pragmatic reasons. The desks were arranged in a sphere so that participants could comfortably see one another and the chalkboard, and could also make use of jotting paper that had been placed on each desk for use by the participants when deemed as necessary. In advance of the discussions, I wrote on the chalkboard a bulleted summary of each prior research finding on psychological distress, the IOM (2007), and NHMRC (2003) definitions of psychosocial care and psychosocial care needs, and barriers to providing psychosocial care as experienced by nurses. These research findings constituted the stimulus materials for discussion. Bottles of water and snacks were available for participants. Three audio recorders were arranged to ensure clear audibility. A pilot was conducted together with the technology assistant prior to each session.

## Participants and Recruitment

A multinational sample of hospital and community based nurses experienced in caring for patients with cancer participated in the focus groups for this study. Participants were recruited from a locally situated nursing professional organization using the purposive snowballing technique. An announcement to 25 local members was made through the organization's gatekeeper. Within 24 hours of the announcement, I received e-mails and phone calls from five nurses who reported their interest in participating in these focus group discussions. During initial telephonic communications with these prospective participants, I explained the study's purpose, voluntary nature, expectations, need for signed informed consent, perceived value of the multinational sample, and inclusion criteria. Two prospective participants volunteered to recruit five other interested nurses using the snowballing technique. I ceased recruitment when 10 nurses had agreed to participate. The networking, snowballing, and purposive sampling technique motivated participants who were willing to articulate their experience through group discussion (Karnielli-Miller, Strier, & Pessach, 2009) to help ensure research answers were optimally answered (Morse, 2003). Recruiting from peers in a professional network had the added advantage for potential future actions that might come about as a result of research (MacDougall & Fudge, 2001). Self selection meant these findings should be considered a cross section "snapshot" (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007, p. 1003). Focus group researchers have claimed five or six members in each group as the ideal number for academic focus groups (Macleod et al., 1996). Using more than one focus group increased the reliability of data by ensuring saturation (Sim, 1998). Rationale for this study's multinational sample selection approach was based on the earlier cited international research findings on psychological distress cited in chapter 1. It followed that all nurses, globally, would be expected to participate in integrated care. The International Council of Nurses (ICN) and nurse researchers made the claim for developing an international perspective of a given clinical problem (Chiang Hanisko, Ross, Ludwick, & Martsolf, 2006; Freshwater, 2003) especially given the current cultural diversity in most patient populations (Freda, 1998). Using a multinational sample of experienced nurses offered different cultural perspectives on the role of the nurse and was considered a logical approach to gain a meaningful set of data that would otherwise have required individual studies. Convenient dates and times for these discussions were arranged telephonically and by e-mail and I made follow-up phone calls and sent e-mails to confirm attendance one week prior to the discussions and again one day before the set date for discussions. I conducted the focus group discussions in the first week of July, two days apart. Before commencing the discussions, participants signed the informed consent form (Appendix A), completed the demographic data sheet, and answered the research question: Is psychosocial care the business of all nurses? Given the diversity of this multinational sample this study makes a "theoretical generalization" about nurses' role beliefs with respect to providing psychosocial care to patients with cancer. Theoretical generalization was explained by Sim (1998) as a type of generalization whereby concepts can logically rather than statistically transfer to other contexts (p. 350).

## Data Collection Method

For this study two focus groups offered data saturation due to the prescriptive nature of the research questions that necessitated moderator involvement. No further groups were needed to substantiate any possible claim for trustworthiness over group dynamics (Asbury, 1995; Morgan, 1997). Social desirability bias was addressed by a recommended strategy that required that all participants answer one question prior to discussion for later comparison (Carey, 1995, p. 490). I used the research questions as a guide to facilitate group interaction in order to answer the research questions (Morgan, 1997).

Following the introductory instructions, participants were asked to suggest an adjective or image of psychosocial care. This approach was based on Morgan's (1997) explanation that the introductory question should ideally center on some shared, meaningful interest and is important to subsequent discussion, as it sets the mood and illustrates that the views of all participants are being sought, expected, and valued throughout. For this particular research, nurses' perceptions of psychosocial care also offered insight into the congruency between that implied in the clinical guidelines and nurses' own perception of psychosocial care. Three key open-ended questions were the remainder of the focus and proceeded sequentially along the following lines:

1. The background provided to participants included earlier research findings on psychological distress, structural barriers as experienced by nurses, and psychosocial care behaviors as subjectively extracted from the clinical guidelines (NHMRC, 2003) that include detect, monitor, document, refer as needed.

Psychosocial needs as defined by IOM (2007*)* were also charted as background stimulus material. I informed the participants that nurses' providing psychosocial care to patients with cancer was something I was interested in knowing about from these discussions.

2. I was interested in knowing what nurses believe about providing psychosocial care to their patients with cancer, whether nurses believe nurses have a role in providing psychosocial care?
3. Given the current research findings about psychological distress in cancer patients, and current structural barriers to psychosocial care, I was interested in knowing what nurses believe it would take for all nurses to take a greater role in the psychosocial care of all patients with cancer and other serious illness. Also, whether nurses would claim that only with increased training would, or should, nurses provide psychosocial care?

Before each group disbanded clarification for inconsistencies in statements was sought at the end of each session (Sandelowski, 2002) and immediately following each session I wrote field notes that included overall impressions to be explored (Morgan, 1997). All relevant data including the survey question, audio-recorded transcripts, interaction data, memos, and field notes were used in the data analysis. According to Duggleby (2005), interaction data address matters such as, what, when, and how certain issues were raised, contradictions, disagreements, tensions, common experiences, resolution, and consensus. Interaction data provided insight into how nurses saw the role of the nurse including about whether those role beliefs could be interpreted as a barrier to psychosocial care. Interaction data for this study is provided in Appendix B.

## Data Analysis Method and Rigor

Smithson (2000) explained that “analyzing group processes is by considering opinions in focus groups as being constructed collectively…collaboratively constructing a joint perspective” (p. 09). Morgan (1997) stated that using a structured approach data collection should be matched by a structured approach to its analysis and reporting, including topics covered in the discussions by each group. In chapter 4, I provide detailed discussion of these differences.

This study used the survey question, verbatim transcripts of the discussions, field notes, memos, and group interactional data in its content thematic analysis (Burnard, 1991). This method of analysis comprised of 14 steps that included setting aside researcher assumptions by listing them in advance and purposely not including them in the question schedule, so as not to lead the participants. Researcher assumptions were color coded to ensure researcher avoidance and facilitate boundary recognition thus better assist in data validity and rigor. Participant validation and peer checking for validation were employed a means to enhance rigor (Burnard, 1991). Burnard’s method of analysis included noting down all things immediately after the discussions notes were taken, reading and re-reading transcripts for general themes were noted, describing and categorizing headings, collapsing and broadening categories as needed, and creating a final list of categories. Subsequently, two colleagues independently generated categories which were then compared and adjusted together, transcripts were again re-read and reassessed, categories were further refined as needed, all coded categories were collected in context, headings and subheadings for coded sections were made according to the research questions and researchers assumptions, and original statements of three participants were checked to confirm their agreement with their original statements fit into a certain category and adjusted. All sections were then re-filed, the research questions were sequentially listed, and participants' narratives were attached and cited in context. Finally, findings were written up and linked to current literature accordingly (p. 462). Burnard's content analysis process was applied to this study's research questions: What nurses believed is their role in the care of patients with cancer? Who should provide psychosocial care to patients with cancer? Whether nurses believed they have a role in providing psychosocial care? What would it take for nurses to take on a greater role in providing psychosocial care? Nurses' impressions of previously experienced structural barriers to psychosocial care, Lazarus's cognitive motivational relational theory, and this researcher's assumptions were all key codes and subsequently color coded in notes, memos, and in the margin jottings of the transcripts. Key codes outline is provided in Appendix C.

I began analysis of the focus group data by jotting down impressions while observing and listening to the group discussions and then again throughout the multiple reading and re reading of the transcripts. I noted contradictions and exceptions, and sought, noted, and checked for context, patterns, and significance. According to Barbour (2005) focus group analysis should ideally proceed from systematically identifying, refining, describing, and analyzing themes a process that required noting patterns, complexities, contradictions, exceptions and, implications for future practice referred to as “analytic induction” (p. 747). In the analysis I also included content and processes of the group discussions across groups (Table 1), as recommended by Barbour (2005).

## Limitations

The general limitations of this study were cited in chapter 1 and included participants’ motivation, social desirability bias, language proficiency of the multinational, multilingual participants and, my skills to monitor focus groups. Also, focus groups can have potential problems that include high levels of inconsistent data, effects of group pressure, social posturing, going off topic and, social loafing, all of which carry the potential to threaten data trustworthiness (Asbury, 1995; Macleod et al., 1996; Seal, Bogart, & Ehrhardt, 1998; Twinn, 2000). It was also plausible that nurses might have sensed disapproval for not providing psychosocial care. Clear explanations regarding the value of honest discussions including not focusing on images of “the ideal nurse” helped avert these problems. However, my clear explanations regarding the value of honest discussions as well as being mindful and watchful throughout the discussions helped prevent such problems. All of the nurse participants were fluent speakers of English. Limitations specific to data collection and analyses included human cognitive limitations that potentially influenced approach to data being analyzed (Sadler, 2002). Sadler’s checklist coupled with participant validation and peer checking in Burnard’s thematic content analysis method helped ensure this study’s rigor and trustworthiness.

## Ethical Considerations

As researcher moderator I had the ethical responsibility to ensure that the group dynamic was such that it would not harm the participants. This was addressed through careful planning at the various stages of focus group preparation, attention to sample size, clear opening explanations concerning overall purpose, plans, and expectations, and providing opportunities for involvement of all members (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007; Jowett, 1996; Karnielli-Miller, Strier, & Pessach, 2009; Winship & Repper, 2007).

Informing participants of the nature of the study, the handling of data, the outcome of the study and dissemination of findings was also an ethical requirement. Each participant signed an informed consent but the voluntary participations component of the signed informed consent was verbally reiterated prior to each focus group discussion, including the option to withdraw at any time. I informed the participants that the sessions would be audio recorded but privacy respected and anonymity maintained through de-identifying participants. All records remained locked and password protected and kept in two separate locations. Ethical requirements also included those with respect to the data analysis. Burnard’s method of analysis required participant validation whereby participants were asked to confirm points in their narratives made during the data collection for validity. Interpretations were discussed, refined, and adjusted as needed in order to address rigor, and prevent distortion or misrepresentation of participant statements (Hewitt, 2007). Both *pro* and *con* opinions were reported in the findings (Brinkmann & Kvale, 2005). Further ethical considerations included preventing harm to nurse participants experiencing disturbed feelings during the discussions in the event they realize that they perhaps failed to notice a cancer patient whom on retrospect might well have been suffering distress. Theoretically, these focused discussions could have elicited feelings of remorse by nurse participants who had in the past perhaps claimed that psychosocial care "is not my job" and oversimplified the importance of psychosocial care, while other participants might have become aware of incongruency between their current nursing care and ideal nursing care and experienced selfdoubt, as a result. To address these possibilities vigilance and clear explanations were given in the opening remarks explained to both groups. Self-awareness concerning clinical practice was acknowledged as a sought after result of focused discussions but at the same time the process should make every effort to prevent participants being overtaken by feelings of negligence whereby they become despondent, for example. To address these ethical considerations I included comments in the opening remarks to the effect that honest and authentic discussions were considered valuable for subsequent patient care. Also, I made every effort to create an ambience of collaboration and value for differences during discussions, including an opportunity for debriefing, either formally or informally, to help prevent harm to participants who might have experienced stress during these discussions (Smith, 1995). I worded the research questions in such a way that they did not "invite defensiveness" (Chase, 2003, p. 85) and stated to both groups that the name of a practicing psychologist would be made available to participants who felt the need after the discussions.

### Reflexive Statement

Personally and professionally as a nurse, I have witnessed and been touched by psychological distress in cancer. These experiences became the motivator of this research. My experiences with psychological distress in cancer also provided the background to biases that influence my stance as researcher (Josselson & Lieblich, 2003) narrowed down to subjective interpretations of nurse passivity and the argument for "where there is a will… ". Morally, now that we know about psychological distress and its very real possibility that it can lead to suicide in some patients, leaving patients in distress while we nurses figure out whose role it is to provide psychosocial care is seen *as* highly questionable. Intellectually, I accepted that my perception of nurse passivity could also be interpreted in a less critical vein, placing the role of the nurse within a social and cultural hierarchical context that must be acknowledged. Emotionally, I was impatient for nurses to take a stand here and get going. As a result, this bias carried the potential to obstruct authentic communications about the role of the nurse providing psychosocial care. By making a conscious effort against communicating my stance during the data collection process, I made every effort to listen and truly "reflect on a mind other than my own" (Josselson & Lieblich, 2003, p. 269). The focus group method was of great benefit in ensuring the necessary "distance" could be maintained throughout.

## Summary

In this chapter 3, I provided an overview of the research purpose, and discussed the rationale for qualitative design, sample and recruitment, data collection method and knowledge expectations, data analysis method and limitations, and ethical considerations. In chapter 4 that follows, I provide a summary of the data.

# Chapter 4: Results

## Overview

The purpose of this qualitative focus group study was to identify nurses' role beliefs and determine whether those role beliefs were a barrier to psychosocial care for patients with cancer. As researcher, I believed that identifying nurses' role beliefs would clarify whether nurses held the belief that providing psychosocial care is considered by nurses as part of their nursing role, thus move health care professionals closer to systemizing the much sought after integrated cancer care. Nurses' role beliefs had remained empirically unknown, according to the literature. A purposeful multinational sample of nurses was snowball recruited for this study from a locally situated nurse's professional network. In this chapter 4, I present an overview of the procedures used in data collection, management, and verification, before proceeding to report the eight major research findings that emerged from this data. Sources that provided the data for this study include survey question, verbatim transcripts of the focus group discussions, researcher memos, field notes, and observations of group interaction.

### Data Collection Process

The primary means of data collection was the focus group interviews. Nurse participants discussed prior research findings on psychological distress and psychosocial care. Following official IRB approval in June 2010 (06-10-10-0074755), the introduction to the research began with my explanation of the purpose of the study, importance of and expectations for all participants to discuss the research questions. Following informed consent, I sought demographic data and participants' answer to one dichotomous survey question: Is psychosocial care for patients with cancer the business of all nurses? Both groups were given the same instructions, the same stimulus materials, and asked the same research questions as noted in chapter 3.

The first focus group discussion was conducted on a week day evening in July 2010 in an international high school classroom in Japan chosen for its conveniently located and its quiet, comfortable setting. The second focus group was conducted late morning in the same setting two days later. Both group discussions were recorded for 90 minutes, although participants in both groups continued discussion well beyond the 90-minute mark after recording had ceased. Focus group 1 was ethnically diverse and consisted of three female nurses and two male nurses. Focus group 2 was also ethnically diverse and consisted of five female nurses. All of the nurses were currently employed and working in a nursing specialty that included oncology, internal medicine, public health, mental health, trauma, obstetrics and gynecology, medical journalism, and surgical nursing, either in the community or hospital setting. Years of experience ranged from less than five years to greater than 20 years. Age ranged from early 30s to late 50s. All nurses had worked in patient populations outside their original culture and most in a second or third language. The demographic characteristics of these participants are provided in Table 1 and topics discussed in Table 2.

Table 1

*Demographic Characteristics of Nurse Participants*

| Nurse | Origin | Exp. | Graduate | Specialty | Age | Gender | Current |
|---|---|---|---|---|---|---|---|
| FG1P1 | America | <5 | Yes | Oncology | <40 | F. | CM |
| FG1P2 | Asia | 5-10 | Yes | Internal | <49 | F. | Hospital |
| FG1P3 | America | <5 | IP | Peds/Med/Surg. | <40 | M. | Hospital |
| FG1P4 | America | 5-10 | Yes | O.R. | <40 | M. | Hospital |
| FG1P5 | America | >20 | Yes | Trauma | <50 | F. | CM |
| FG2P1 | M/East | >20 | Yes | Public Health/Obs/Gyn | <60 | F. | Community |
| FG2P2 | Asia | >10 | No | M/Surg/Peds/PH. | <60 | F. | Community |
| FG2P3 | America | >10 | Yes | Public Health | <60 | F. | Community |
| FG2P4 | America | 5-10 | Yes | Peds. | <60 | F. | Medical Journalism |
| FG2P5 | Africa | >10 | Yes | M/Surg/Mental Health | >40 | F. | Community |

*Note.* Total N= 10. F=8 (80%). M=2(20%).

Table 2

*Topics Discussed Across Focus Groups*

| Topics | Group 1 | Group 2 |
|---|---|---|
| Nurses Role Beliefs | D | D |
| Perceptions of Psychosocial Care | D | D |
| Barriers to Psychosocial Care | D | D |
| Perceptions of Provider Domain | D | ND |
| Origins of Nurse's Role Beliefs | D | D |
| Diagnosis and Providing Psychosocial Care | D | D |
| Perceptions of Greater Nurse Involvement | D | D |
| Need for Increased Training | ND | D |
| Culturally congruent nursing care | ND | D |
| Guideline expectations for psychosocial care | D | ND |

*Note*. D= Discussed; ND=Not Discussed.

The provider domain topic was not expanded upon in the discussions held by nurses in the second group, most of whom were employed in the community setting. In contrast, all nurses in the first group were employed in hospital settings and discussed the provider domain in detail. Nurses in the second group focused primarily on the nurse as an autonomous, independent professional working in a wider system of care that may involve fewer other health care professionals. Group 2 nurses had greater cultural variation and more nurses who had longer experience working outside their own culture. These experiences may explain their deeper discussions on culture as a critical force in effective psychosocial care. Nurses in the first group discussed their perceptions of the psychosocial care behaviors implied in the clinical guidelines but neither group discussed these in length. All nurses did, however, provide helpful suggestions regarding the dissemination of those guidelines discussed later herein.

Participants of the first group appeared pleased to be participating, and were lively and quick to enter discussions. There was laughter and joking, yet the participants took the questions seriously and remained on task throughout. Participants were communicative and cited experiences. Opinions converged, although agreement alternated as they answered the research questions. Initially, out of concern that the participants might not be willing to talk, probe questions designed to seek evidence were preplanned and color coded for easy access (Rubin & Rubin, 2005). However, the answers to the potential probe questions surfaced from the discussions and the participants discussed the research questions without much prompting. Also of concern was my own level of involvement: I strove to maintain balance between my role as the researcher, observer, and moderator, and to be not be too forthright lest the dynamic be disturbed yet ensure that the research questions were being answered. The value and strengths of the self-contained focus group method were evidenced during this data collection. Specifically, through its underlying demand for limited moderator involvement, I was forced into the listener role, resulting in greater confidence in the data.

A minor change was made after the first group discussion. Along with my assistant, I seated myself further from the participants during discussions. This change was made after one participant in the first group appeared to be distracted by note taking of the researcher assistant, albeit a short lived distraction and despite opening remarks to the effect. Increasing physical distance from the group allowed participants to feel less "under the microscope" and also allowed for my easier observation.

Participants in the second group were also friendly and appeared pleased to be participating. The discussion was initially quiet and then became lively. Participants were on task throughout; there was laughter and complimenting of one another's opinions and ideas. Opinions were diverse. Dominance was not perceived in either group although some participants were naturally more vocal than others. Collaboration was evidenced as the participants discussed practical solutions. This group also answered all of the research questions. Participants in both groups addresses points of conflict respectfully by "ethical reasoning" whereby persons seek out expanding explanations in order to grasp an understanding of the wider context (Fairchild, 2010, p. 358). This point was illustrated as group members discussed the role of the nurse wherein one nurse repeatedly described what appeared to be a combination of medical and nursing care and another nurse appeared to find this combination quizzical at first but then commented

> P5: I see, yes, as you say…in Kenya, where they don't have many doctors…so that explains (her) emphasis on nursing and patient education and medical, and, so much medical, yet both…psychological issues in cancer care (focus group 2).

Initially, my impression was such that these nurses appeared willing to talk. As time passed and discussions flowed, however, I sensed a shift from "willingness" to talk to a "need" to talk. Below are concluding comments from two participants:

"This was great…it made us sit and pause about our clinical care." (focus group 1) and, "Time was too short…we need to do this again." (focus group 2).

### Data Management

Focus group audio recordings were transcribed verbatim by a professional transcribing service. Several copies were made, and the original was stored in a safe locked and password protected computer. Working copies were kept in my desk when not in use (Patton, 2002). One set of the audio recordings accompanied the transcripts for accuracy checking. A data management system (Table 3) was compiled and arranged for concurrent use during the analysis process.

Table 3

*Documents Used for Managing Data*

List of research preplanned questions
Running Table for '*knowledge sought knowledge attained*
Record of validated statements'
Steps to Burnard's (1994) Content Thematic Analysis Method
Analysis rigor check (Sadler, 2002)
Findings consistency chart
Group interaction field notes*
Memos*
Key codes chart*

*Note:* * Indicates samples provided in Appendices B, C, and D

**Data Analysis, Rigor, and Validity**

Data were analyzed using Burnard's (1991) thematic content analysis method, which involved 14 steps. Sadler's (2002) cognitive biases checklist was used concurrently alongside Burnard's thematic content analysis method to increase trustworthiness (Miles & Huberman, 1994). Further steps included the following: Verbatim transcripts of the discussions and audio recordings were checked for accuracy, running notes that connected the research questions were made while reading and re reading through the transcripts and memos. Possible themes were noted, questions, and or comments were jotted in the margins and throughout the memos, as were explanations, plausible alternatives, contradictions, and exceptions in an ongoing process in my research journal (Patton, 2002). Impressions of overall findings were explored and themes not supported by the data were discontinued (Bloomberg & Volpe, 2008; Miles & Huberman, 1994; Patton, 2002). Some preliminary categories were established in advance based on the research questions. New categories emerged and others were collapsed. Checking with respondents was conducted during data collection and throughout data analysis. Two peers independently compiled codes and categories, which together we then discussed, modified, or refined accordingly.

## Findings

Findings that emerged from this qualitative focus group study are presented in the following paragraphs. Quotations from the transcripts were cited in context to avoid misrepresentation (Bloomberg & Volpe, 2008; Miles & Huberman, 1994) selected to illustrate the particular positions of nurse participants as they discussed the research questions: (a) what nurses believed is their role in caring for patients with cancer, (b) whether nurses believed they have a role in providing psychosocial care for patients with cancer, (c) what nurses believed it would take for nurses to take on a greater role for patients with cancer, and (d) nurses' impressions of current structural barriers to psychosocial care. Participants (P) are abbreviated and both anticipated and unanticipated findings that emerged from this data are discussed.

**Nurses' role beliefs**. This was the first finding in this study based on the research question designed to identify nurses' role beliefs in caring for patients with cancer. Prior to beginning the discussions participants were asked their response to the question (psychosocial care for patients with cancer the business of all nurses). One nurse responded as unsure on the survey but verbalized during the discussion "nurses are willing and capable of providing psychosocial care" (focus group 1). Also during the discussions, this same participant told of his experiences with suicidal patients in the in-patient setting including how he had spent time discussing coping strategies with suicidal patients using a model of care that he had learned in nursing school. This contrast suggests that his different answers were due to his being unsure about the wording of the question per se. A second nurse handwrote on the survey sheet that, "psychosocial care is the business of *all* nurses for *all* patients" (focus group 2). It is plausible that her expressed conviction on this point is connected to her personal experiences with cancer, a factor she speaks about in the discussions. Throughout these discussions, nurses in both groups steadfastly maintained that providing psychosocial care is within the nurse's role.

Nurses indicated that role beliefs were dynamic, developed through education, mentoring, and experience, including life experience, and interwoven with one's personality and family background. Nurses indicated that diagnosis was not related to whether or not nurses provide psychosocial care; "doesn't matter, whatever the disease" (focus group 1) "Patient, no matter what, cancer or some other illness" (focus group 2). Nurses working in hospital-based systems of care reported they did not feel supported by other health care professionals in providing psychosocial care as illustrated in the following narratives:

> P4: (Psychosocial care) is our role but other health care professionals don't always see it that way…. They see psychosocial care as *mental health* [emphasis added] … in the domain of social workers or mental health professionals…not in nursing. I nursed in Japan and US. In Japan we are expected to do everything, but in the US

> the nurse may be told by the social worker 'you don't have to do this…this is *my* [emphasis added] job.
>
> P2: Providing psychosocial care *is* our role … *definitely* [emphasis added]…psychosocial care and communication strategies are the foundation of nursing…(group showed agreement through nodding and laughter). Psychosocial care is what distinguishes us, the nursing role from medical role…(group laughter)…the role of the nurse also includes coordinating role if *I* can't do it, then I should get someone who *can* [emphasis added]. I can't be everything to everyone but I should try and find someone who can help. Continuing and expanding on her point:
>
> P2: I am a cancer survivor. I finished chemotherapy in December last year, malignant lymphoma. So, I have been a consumer of Japanese care for cancer patients…I was really impressed with the role that nurses seem to have in doing…making sure that everything was coordinated…I could ask at any time, any questions got answered…I saw the nurse's role as being you know, *aware* [emphasis added] of my needs and making sure they got met, not that the nurse herself necessarily did it. (focus group 2)

Expressions of contradiction were evident. On the one hand nurses argued that psychosocial care was a fundamental nursing activity and as such providing psychosocial care *is* within their professional role *y*et psychosocial care was described in terms of psychosocial care being "an area of nursing," "going above and beyond," "going the extra mile," and "touchy feely" nursing that required "nurse motivation" (focus groups 1 and 2) and highly varied. Such descriptions went unchallenged. Nurses apparently noticed but did not fully discuss any perceived differences in their own understanding of psychosocial care and the psychosocial care implicitly assumed in the IOM guidelines. Nurses indicated a need to have their provider role fully authenticated and legitimized, as illustrated in the following narrative wherein a nurse participants pointing to the IOM definition of psychosocial care noted on the chalkboard stated:

> P2: We have to decide…how many nurses, statistically speaking, are aware that *this* (pointing to the IOM definition on psychosocial care) is part of their job, and actually do it…. Some of this (psychosocial care) seems intuitive…we are doing it every time you come and talk to the patient. (focus group 1)

Participants cited lack of resources, nurse motivation, and personal stress as reasons why nurses might not provide psychosocial care acknowledging the differences between should do and actually do. Stress and emotions surfaced in this finding indicating the impact of psychological forces as covert barriers to psychosocial care. One nurse indicated that personal stress while realistic and humanly understandable was nevertheless unacceptable reasoning for avoiding what was seen as the nurse's professional responsibility; "nurses are not to be let off the hook here" (key respondent, personal communication, August 23, 2010):

> P3: Psychosocial care is very relevant to nursing and nursing needs to play an active role…although, that active role is diminished if the resources aren't available to the nurses to act upon.
>
> P2: Yeah…some nurses won't go the extra mile. (focus group 1)

> P4: I suppose its ‘cos some nurses are naturally drawn to certain areas of nursing, psychosocial care being one of those areas…(although) the system itself doesn’t really carry the expectation for nurses to provide psychosocial care. (focus group 1)
>
> P4: Some nurses can’t handle it (providing psychosocial care). Some stress out. Some can’t do this one but, you know as a nurse she is required to take care of *some* (psychosocial care)…. She doesn’t have to be involved in full psychological care if she doesn’t want to, but some…she *has* [emphasis added] to provide care.
>
> Contesting this position, P2 responds: It (personal stress) *can’t* be the end of the line…if the nurse lacks the emotional resources, and let’s be realistic here…She should find someone who can…I can’t be 100 percent 100 percent of the time…I can’t do respiratory therapy…I *can’t* [emphasis added]…but I have to find someone who can…if it’s something I can’t deal with then it is my responsibility to find someone who can. (focus group 2)

Nurses suggested that unless patients themselves see the nurse as a provider of psychosocial care, and “the system” supports the nurse here, avoidant nurses would likely continue to avoid psychosocial care.

> P2: Would cancer patients *know* that nurses are expected to play a psychosocial role?
>
> P3: No.
>
> P2: So, it takes it back.
>
> P3: nodding, responds: It is a vicious circle, that’s really what it is…and I can’t explain. I can’t give you any reason as to *why* [emphasis added] nurses don’t

> (provide psychosocial care)…we don't hold them accountable…but until we develop a system to hold people accountable…it's like saying, "I'm not going to address psychosocial needs." (focus group 1)

Seeking clarification on nurses' claims that providing psychosocial care was within the nurses' role the researcher was responded to with loud laughter from the group, understood as unquestionable; without doubt.

> P5: (smiling) Oh, definitely! That's the difference between the medical and nursing role. The nursing role is to provide psychosocial care (continues smiling. Other group members also continue smiling lasting several seconds, in silence.
>
> P2: (contemplatively) Mmm, you know, my initial education…our first clinical was in psychiatric nursing (members expressed apparent surprise) because the principal held that psychosocial care and communication strategies are the foundation of all nursing…communication with all patients.
>
> P1: In Lebanon, psychosocial care is part of your daily work (as a nurse)…you do everything, you are expected to do it. (focus group 2)

**Concepts within psychosocial care.** This was the second finding in this study. A summary of current research findings on psychological distress as a universal clinical phenomenon, and the clinical guidelines designed to prevent psychological distress in patients with cancer, was used as stimulus materials for the discussions. Participants were asked to cite an image or adjective of their understanding of psychosocial care (what do we mean by psychosocial care, what might psychosocial care look like?). The purpose was to seek an understanding of levels of congruency between policy expectations and nurses’ personal beliefs. Both groups spent considerable time on this question. These nurses reported that providing psychosocial care to all patients was considered within the nurse’s role because nursing is centered on “wellness and illness” (focus group 2). Regarding the distinction between comfort care and psychosocial care, and whether nurses perceive psychosocial care as a specific stand alone nursing intervention that would necessarily include direct inquiring, and discussing psychosocial needs with their patients, nurses responded: “How are we going to know the patient’s psychosocial needs?” (focus group 1). The nature of psychosocial care was described in terms of being, “soft, not measurable, making sure patient is not isolated, or self isolated, being connected with the patient, hand-holding stuff, requiring ‘guts’ ” (focus groups 1 and 2). Psychosocial care was described in terms of being “an area of nursing” (focus group 1) on the one hand and authentic nursing care; a dimension of holistic nursing on the other. Behaviors specific to psychosocial care included assess, discuss, monitor, and refer out as needed, according to NHMRC (2003) and IOM (2007) behaviors and concepts that appear interventionist given the ultimate goals to improve detection, diagnosis, and treatment of distress. Nurses discussed monitoring for distress and stated that they failed to monitor for patients’ psychosocial needs. Nurses’ narratives indicated abstract concepts of care and support on the one hand, and concrete “coordinating patient needs” (focus groups 1 and 2) on the other. Nurses also indicated that they did not assess for psychosocial needs but claimed that assessment without a validated tool was problematic. Regarding discussion with the patient, the nurses indicated that discussion was a reasonable expectation but discussion should be acknowledged for its essential complexities noting that not all cultures will necessarily find nurse initiated open discussion about psychosocial needs acceptable. Knowledge about patients' cancer disclosure, literacy, religious beliefs, and culture were all claimed as essential information needed by the nurse before discussion could be considered ethically appropriate. Also, one nurse suggested that some patients may have a fatalistic interpretation of their cancer diagnosis namely, that "this diagnosis is from God" and seek support from their family, and in their religious spiritual values (focus group 2). Nurses also stated that the types of discussions would depend on where the patient is on the continuum of care:

> P5: There are cultural differences in disclosure of diagnosis…some patients may not be aware of their cancer diagnosis…and the education level of the patient and his or her family.
>
> P3: Yes, what are you going to educate the old man in my country, Kenya?"
>
> P4: (Nodding in agreement): In Japan as well. Many patients, about 50 percent have not been informed of their diagnosis…We have to *know* [emphasis added] the patient.
>
> P2: We have to explore what the patient's understanding of cancer is.
>
> P1: We have to know what beliefs they have. The love and support they get from the family (for a patient in the Middle East) is really, very big and because of that they build hope and it may make them deeper into their religion.
>
> P5: Empathy they can receive or not receive, a lot of times people don't want anybody to know that they have it (cancer)…depends on the person's personality,

> family, culture, expectations, and their knowledge about what cancer is. (focus group 2)

Nurses indicated that *referring out* appeared to be the most practiced psychosocial care behavior including referring to peer support groups. However, according to the hospital based nurses in this group nurse referrals were unlikely to be accepted by other health care professionals implying hierarchy, territoriality behaviors, and lack of nursing authority or independence to proceed with referrals:

> P4: If I refer out and the primary care physician says, "No, I don't think there is an issue"…then what? (focus group 1)

Discussion and referring out were the behaviors most often cited by these nurses. Detection of distress was not mentioned, and assessment was associated with a quantifiable tool. Also, during discussion about psychosocial care, one nurse asked the group*:* "Who is going to know that psychosocial care was done…is it something we discuss in report? Absolutely not!" (focus group 1)

These nurses also indicated that the lack of a universal definition of psychosocial care as well as the nature of psychosocial care itself would likely contribute to the problem with avoidant nurses, and level of support available for nurses in the provider role; support by peers as well as other health care professionals:

> P3: So, if there are validated tools that we can administer as nurses when they are coming in for their medical follow-up care, that's an opportunity…if we know they are coming in, we can have more time with the patient.
>
> P5 Responds: And, that makes it okay for them to seek care.

> P4 Joining in: So you feel they have a stronger chance of being referred?
>
> P3 Responds: I--I do because especially if the doctor. They can't walk away from that you know. They can't walk away from quantitative analysis.
>
> P3: Continues: You know if we have *something,* the recognized tool, as nurses, everything would be accepted…I think that would help…I would add that to my nursing notes…it (validated tool) is a motivator.
>
> P4 Responds: The question comes does a physician *read* nurse's notes? (focus group 1)

During discussions on the IOM guidelines and IOM definition of psychosocial care, one nurse perceived the terminology "psychosocial care" as confusing:

> P1: I don't even know the Japanese word for *psychosocial* care, it could be more *mental* health, but I didn't have any training with social care because we have nursing, and there's a difference, we (nurses in Japan) wouldn't do anything like consulting with a doctor.
>
> P3 Responds: That's because they (Japanese hospitals) have caseworkers on the floor walking around and *they* address, the nurses don't have to address it as much. Nurses (in Japan) won't necessarily jump in during a case conference, they may talk more about it if the physician leaves the room, they'll step forward, but they will not engage or address those (psychosocial) types of issues in the group setting.
>
> P1 Adds: We do a lot of interaction with the families…but sometimes it is hard because, I don't know, just they- they will ask direct questions but sometimes we

> can't …we will say, OK we'll talk to the doctor and let you know what's going on, but then the doctor will do, just do the routine, like it (psychosocial care) is not necessary.
>
> P4: I do believe psychosocial care is -- it really needs to be defined universally, you know, Australia or America they have some common things here but, you know, if we don't have the translation for it in Japan…I think universally, as nurses it's hard to really follow these guidelines…if we haven't agreed on, empirically, what it means to provide psychosocial care. (focus group 1)

Differences in cultural expressions and approaches notwithstanding, nurses nevertheless cited an apparent mixture of behavior and attitude as they described their beliefs on psychosocial care; role beliefs indicated a shared understanding of the abstract components of psychosocial care based on nurturance theories of nursing as illustrated in the following expressions:

> Listening to the patient…not trying to interpret, asking the patient directly…discussing directly (focus group 1) Guidance… Being proactive (focus group 1)… Supportive… (focus group 1)… Holistic care; looking at the whole person…(focus group 1) Depends on the condition of the patient, but talking to patient and family to ensure good care (focus group 1).
>
> Talking with patient about their stress from the cancer and treatment, and what to expect in their medical treatment...including, helping them *accept* their illness…medical, social, psychological care…patient education…(focus group 2).

> *Engaging* with the patient…what strikes me is the word ‘social’, the idea that you are not doing it by yourself…support and involvement… not leave the patient in isolation…care that ensures Hope…not being *socially* isolated and not being without hope, even if its not cure, there is always hope for something…(focus group 2)…family involvement…listening to the patient…you have to listen, by listening you accept the patient …accept the patient and go from there…you assess, okay, what can I do as a nurse? (focus group 2)…requires understanding of their cultural, social, and psychological circumstances and needs…(focus group 2)…provide comfort to patient and family (focus group 2).

Approximately 20 comments into the discussion one nurse smiled broadly as she shrugged her shoulders, turned her palms upwards and leaned forward to face the group: ”So there, it’s not really a *definition* (of psychosocial care)…these are the ways we stand as a nurse, right? (gentle laughter) (focus group 2).

The need for future research was evidenced in this finding regarding the definition of psychosocial care. Differences in concepts of psychosocial care are summarized in Table 4.

Table 4

*Differences in Concepts of Psychosocial Care*

| Nurses Narratives | International Cancer Care Networks |
|---|---|
| Supportive, Comfort, Intuitive anticipating Needs, Engaging, Holistic, Includes Family, Patient Education about Medical Treatment, Psychological Factors, Handholding, Involved in Care, Communication, Listening, Mental Care, Empowerment, Referrals, Networking, Coordinating | Detect, Diagnose, Treat, Prevent Distress, Monitor, Refer Out, Follow up, Discussion |

*Note:* For the purpose of this study the word *Concept* was interpreted as "a mental pattern that is in the mind of the person who says it or hears and understands it" (Joseph, J.E."2004) *The Linguistic Sign*. Cited in *Saussure*. Cambridge University Press, Ed. Carol Sanders (2004, p. 63).
* International Cancer Care Networks include: NHMRC (2003), NCCN (2006), and IOM (2007).

**Barriers to psychosocial care.** This was the third finding in this study and based on the research question wherein nurses were asked their impressions of the current lack of time, need for further education, and lack of skills barriers to psychosocial care. Current structural barriers were substantiated. Nurses further recommended that lack of resources, nurse motivation, and systems of care that limit patient contact and fail to support authentic nursing be included into the current list of barriers to psychosocial care discussed in this literature review. Personal stress and nurse motivation indicated psychological forces as covert barriers to psychosocial care. One nurse disputed the education barrier on the grounds that there are plenty of educational resources available for nurses. The education barrier became an area of conflict that was resolved after the discussion sessions by the sharing of educational resources. Nurses indicated that while structural barriers should not prevent nurses from finding ways to ensure that psychosocial care was provided, systems of care contrary to nurse's perception of authentic nursing could nevertheless lead nurses to burnout:

> P3: This list (of barriers) is accurate but inconclusive…need to add, *systems of care* and *resources*.
>
> P2 Responds: Need to add, *nurse motivation…*motivates to help.
>
> P3 Responds: Wow, that's fabulous, yes.
>
> P2 Adds: Some nurses don't care.
>
> P3 Adds: Or, don't want to care. It's easier not to care.
>
> P2 Responds: Or (nurse is) too busy to care, but.
>
> P4 Adds: Some nurses go above and beyond because that's just the way they are…it could be nurse dependent…you need someone in this (role) that would be more open to doing, you know, those types of things, (going) *above and beyond.*
>
> P2: Am not saying they shouldn't do it (psychosocial care), but it must be very discouraging for nurses in America today. How're you supposed to do it? This is very idealistic (pointing towards the research findings) what you do for psychosocial support? But then I think, the *coordinator* [emphasis added] role if you can't be there to follow through.

> P3 Adds: We can't just assume we can do it because we are nurses…we can't do that. I would try to deal with…I'll *listen* [emphasis added] to the person…I know my limits, but if I get education, I get a little more to it…nurses need more education on psychology.
>
> P2 Responds: Education *is* available…resources are out there…if nurses want to improve themselves you know, they can always…I just took an on-line psychiatric course. (focus group 2)

Nurse discussions of barriers included "systems of care" that were perceived by these nurses as capable of blocking or promoting psychosocial care, as illustrated in the following narrative:

> P3: Several years ago when I was a charge nurse, there was a nurse on the unit, and she worked more shifts than probably anyone else, and when she was on shift she gave 110 percent, certainly a lot of the psychosocial (care). Patients absolutely loved her. That's because she was so into patient care. But, when it came to evaluation time, she was often downgraded because she didn't do lot of the extra-curricular outside the unit activities. You know, she wasn't on a lot of committees. Because, she always felt that her passion and her *role* [emphasis added] were on the unit and taking care of patients, which it was, in many ways…you know. I remember fighting for her when it came to evaluation time…the way I approached it to the committee…was, "Who would you want at *your* [emphasis added] bedside when you were sick?" and everyone of them said, "Her" and I said, "Wow! So, is there anything wrong with being a nurse's nurse?"

> Eventually, we moved her way up in the ranking system trying to overlook the fact that she didn't necessarily do this extra stuff…but our system doesn't necessarily support nurses who are *compassionate* [emphasis added] …they want the nurses who *do* the most, *know* the most, and know the most *clinically*, do they not? They are *not* going to reward the nurses who are passionate or who really do reach out. And, because this is emotionally draining to give a 110 percent continuously…it's hard sometimes…and you start hesitating giving yourself continuously and putting in the emotion and the passion…I don't know that our system per se *supports* [emphasis added] nurses who look at and promote psychosocial care…they want, who gets the most consults, not to spend the most *time* [emphasis added] on consults…who spends time at the bedside talking to a family, you know. (focus group 1)

**Nurses and greater involvement in psychosocial care.** This finding answered the research question concerning what nurses believed it would take for nurses' greater involvement in psychosocial care. Nurses claimed that while life experiences positively influence nurses' efforts to carry out and ensure authentic holistic care, ultimately it is nurse leaders who needed to show greater leadership and mentoring for junior nurses:

> P3: All too often nobody goes back to the bedside to teach it to the junior nurses.
>
> P2: Like asking permission to touch the patient before I touch him?
>
> P3: When you are ask the patient how he is doing and he says, "not real well" … what does a 20 year old nurse say to that?
>
> P3: Again, you need years of experience.

P1: And, you got that experience from mentorship. (focus group 1)

Nurses indicated the need for individual nurses to take a stronger stand and the need for hierarchical assistance in doing so. Nurses suggested this was especially important given the *systems of care* barrier. Nurses discussed solutions for encouraging nurses' greater involvement as illustrated in the following narratives:

> P5: A big plan approach…so it can be modified and everybody knows the plan and then distress can be identified at different times.
>
> P4: Somebody has to emphasize it (psychosocial care) in order for it to happen and become habit…somehow it has to come from the top down and it has to be pushed continuously…but, until we tell them it has to be pushed, it won't be pushed. (focus group 2)
>
> P4: I think, really, nurses have to take ownership of psychological care…nurses have to be recognized as having ownership of that, by other colleagues and healthcare professionals…as patient advocates, we can take ownership of *this* [emphasis added] (psychosocial care). (focus group 1)
>
> P3: Somehow (have it) built into the assessment actually something they (nurses) *have* to do. I hate to say *force* [emphasis added] them, but.
>
> P2: We have a lot of practice in writing objectives for physical needs…we can write measurable, behavioral objectives for physical needs. But I think we can develop this and write…emotional or psychic things as well, and just describe this, I mean, put that as a goal, we can do it. The institution has to be working towards it. (focus group 2)

Some nurses stated that the provider domain is not limited to nurses; all health care professionals should play a part in psychosocial care:

> P4: I think *everybody* [emphasis added] should provide some sort of psychosocial care…anybody that comes in contact with patients should have some sort of training in psychosocial care because nobody should be inept at picking up some of the signs and symptoms.
>
> P5 Adds: Whoever spends time with the patient. You might give him (the patient) a bed bath one day and then you come in today and say, “Hey, something is odd here, something happened. He’s a little more anxious or something”.

Some nurses stated that nurses should be involved throughout the patient’s care. (focus group 1)

The idea of collaborative care and establishment of a team approach was welcomed by these nurses

> P4: It (patient care) has to involve nurses from the beginning…we need to be involved.
>
> P2: I think we have to make a better system like, you know…*team* [emphasis added] support for the patient…it’s so important from the beginning to the end that they have somebody, you know, as they go along. Best as possible, plan their 6 or 9 months of treatment or even beyond…it’s probably the perfect type of help. (focus group 2)

Nurses self-reported that they were poorly informed about the findings of psychological distress research in patients with cancer. Discussing the published research findings on psychological distress that were noted on the chalkboard, one nurse participant pointed to the chalkboard and commented:

P4: Nurses *outside* [emphasis added] oncology should know about these findings (focus group 1).

Finally, also in discussing what it would take for greater involvement, nurses were able to offer practical helpful solutions to ensure more comprehensive education for all nurses. Some of these participants suggested making the completion of a standard number of hours beyond one's area of interest or current practice, as a mandated requirement for nursing licensure and re-registration. Different areas of nursing would necessarily include research findings on psychosocial distress and psychosocial care.

**Differences in hospital and community based nurse experiences.** The focus group method allowed this researcher to directly observe and interpret participant interaction as they answered the research questions. While comparison of group discussions per se is not considered a goal in the focus group method (Morgan, 1997) it was interesting that focus group two discussed at length the importance of the nurse making every effort to understand and integrate the cultural background of the patient into nursing care, including religious and spiritual beliefs. The participants in this second group were more ethnically diverse and employed in community based nursing. The participants who formed the first group were all hospital based. Both groups claimed that psychosocial care was the role of the nurse. Hospital based nurses also claimed that other health care professionals should also provide psychosocial care. Differences in community based and hospital based nurses' experiences are noted in Table 5.

Table 5

*Differences in Experiences between Community and Hospital based Nurses*

| Topic | Community based Nurses | Hospital based Nurses |
|---|---|---|
| Discussion with the patient | Nurses must have knowledge of patient's cultural background, interpretation of illness | |
| Contradictory nurse evaluation systems | | Significant barrier<br>*"The system doesn't value compassionate nurses…they want the nurse to know the most and do the most…they don't value bedside nursing…"* |
| Patient education | "*Over rated*"… a mechanical tick box activity "*empty words*"<br>*"Patient literacy"*<br>*"Patient may not be able to absorb the education"* | |
| Period hospital stay | | Brief hospital stays further aggravate the lack of time barrier |
| Nurse input | *Essential " we should be involved all the way through*" | *"Nurse referrals not accepted…not possible*"<br>*"Unsure whether nurse referrals would be honored…"* |
| Monitoring and Detection and Diagnosis of Distress | | Questioned. *" Who reads nurses' notes anyway? "If we had some validated tool "they couldn't walk away from that".* |

**Multinational culturally diverse sample of nurses.** These groups of multinational nurses all experienced in transcultural nursing revealed more commonalities than differences although nurse from the Middle East included attention to religious and spiritual values amongst her perceptions of a patients care needs. Nurses from America and Japan emphasized literacy and diagnosis disclosure. The nurse from Kenya emphasized religious and spiritual values as well as literacy needs.

All nurses in both groups claimed that providing psychosocial care to all patients was the role of the nurse. Nurses' origins of their nursing education indicated individualist and collectivist differences in psychosocial care although the ultimate implications for nursing care action were the same for all nurses from all cultures involved herein, and supports the earlier finding of this study that nurses stated they should be involved in patient care throughout. While nurses from Kenya, Asia, and the Middle East approached psychosocial care mentioning the role of the family wherein "support and love from the family is very big" (focus group 2) and nurses from United States spoke also about "empowering patients towards self help resources" (focus group 1).

**Focus group method and collaboration.** Group interaction was noted by the perceived enthusiasm for discussing nurses' professional role and nurses' beliefs. Further, the use of prior research findings to focus the discussions contributed to what appeared to be a free and focused flow of dialogue, and collaborative search for solutions designed at improving patient care. Gentle laughter, group laughter, sympathetic silence, and encouragement among the participants of both groups, even when opinions differed, were observed throughout. Nurses' interaction in these groups indicated sharing and constructing knowledge together (Stevens, 1996; Webb & Kevern, 2001; Wibeck, Abrandt Dahlgren, & Oberg, 2007) throughout the discussions. One such example was noted during a discussion on providing support and the role of the nurse and the family wherein one participant, drawing on his experiences as father of a child with cancer stated:

> P2: The *family* [emphasis added] plays a big supportive role for the patient.
>
> P4 Responds: Yes but, how much did your being a nurse play into that do your think?
>
> P2 Nodding, responds: Yeah, probably a lot. (focus group 1)

During further discussion of whose role it is to provide psychosocial care:

> P3 and P5 both respond in chorus: *Everyone's* [emphasis added] role"
>
> P3 Takes up the point: It's like with suicide…we are told we are *all* [emphasis added] responsible.
>
> P2 and P5 responded in chorus: Laughter.
>
> P4: Yeah, but we need resources.
>
> P1: Or, empower patients to *find* the resources.
>
> P3: But…we let's face it, we drop the *monitoring*, and we never *follow up.*
>
> P4: But we end up seeing them later, for pain (group laughter).
>
> P3: Exactly! (focus group 1)

Group interaction was further illustrated during discussion of nurses' perceptions of what it would take to have greater involvement in psychosocial care:

> P3: Top-down…nurse leaders…it's like handwashing…that came from the top down; "Did you wash you hands?" We could do the same thing for "Did you talk to your patients today?" (group laughter). (focus group 1)

This suggestion was later developed by these nurses into a project referred to as a "sit-and-pause" reminder for psychosocial care. The reminder project is provided in Appendix E and discussed in detail in chapter 5. Group interaction and collaborative solutions was further evidenced in discussions of what nurses believed it would take to ensure patients' get the help they need:

> P5: In the United States, there are states that require CE for licensure. What states *could* [emphasis added] do is make sure that those CE requirements include different areas.
>
> P2 turns, leans toward P5 and responds with enthusiasm: Ohhhh, how creative! Yes, you could make it so that CE's require so many hours on topic A and so many hours on topic B…say, 3 units have to be psychosocial care, for example.
>
> P5 Nodded affirmatively.
>
> P2: More structure…
>
> P5 (smiling): E*xactly*! (focus group 2).

Other members appeared to contemplate this suggestion for mandating continuing education across areas of specialty. Participants smiled, nodded in agreement and appeared satisfied. A third example of co-construction of knowledge through group interaction was observed during discussions of research question regarding the role of the nurse in caring for patients with cancer wherein patient education was raised:

> P2: I just want to add to that point about *patient education* [emphasis added]…. you know, my mother, 80 years old had a mastectomy and chemotherapy 3 years ago, in the US and they wanted her to do it *outpatient* [emphasis added]… overnight. No counseling. Can you *believe* [emphasis added] that? Anyway, I said, "no there is no way that is gonna' happen". Anyway, she stayed in for one night, which wasn't very successful (ironic laughter) because she fell out of bed…

(Group members' grimace; verbal utterances in apparent sympathy) but she went home the next day, and I was there when the RN came to visit. I said to the RN "what happens to those patients who don't have an RN daughter in the home?" and the RN said, "they (patients) end up back in hospital with more visits and more pain" (audible group member utterances of "*mmmm,"* nodding). So, how are you supposed to provide psychosocial care? You may *want to* but how are you supposed to do it? Circumstances discourage it. They told her the side effects would take about one month to subside, but…anyway, *patient education*, [emphasis added] I bet it was charted that way. There was not a chance she absorbed *two percent* [emphasis added] of what she was supposed to have been taught...so much for *patient education*. You know, on paper, "*patient was taught."* I'm sure it was charted that way.

P3: Yes, in the US…I worked in both Japan and US and I know what you mean… insurance companies have too much power…you have no time…in the US you have so much paper work you have to do it before discharge and you have to hurry up (both arms sweeping gestures) 'cos there is someone else coming in…it is frustrating, not only for nurses, but and am sure it is for doctors as well…but here in Japan patients stay longer…some say *too* [emphasis added] long, but…(quiet laughter)…in Japan we can get to do a lot more.

P4 picking up the point: In Kenya we (nurses) also do a *lot* [emphasis added]. The patient stays longer and we try to give *lots* [emphasis added] of counseling, until the patient *accepts* the illness. We *have* to (understood as *should*) counsel the

> patient and relatives. The nurse is too overworked. There is not enough time for the patient. (focus group 2)

**Clinical significance of psychosocial care.** A theme that emerged from this data concerned the clinical significance of psychosocial care. Nurses' narratives about psychosocial care were curiously absent of vocabulary that would indicate understanding of the clinical significance of psychosocial care; why it was, and remains, important that all nurses, who had hereto espoused to the principles of psychosocial care, provide that care. Nurses neither hinted at nor mentioned the clinical significance of psychosocial care in general, specific to patients with cancer, or for patients with other chronic existential illnesses (Table 4). Nurses' descriptions pointed to the what's and how's but none to the why's of psychosocial care, key vocabulary that one would necessarily expect include risk, health outcome, and/or prevention. Nurses' cited concepts of psychosocial care appear directed at support, communication, listening, engaging, and intuitive care.

## Summary

In this chapter 4, I reported the eight major findings that emerged from these focus group discussions. The purpose of this study was to identify nurses' role beliefs about caring for patients with cancer. Nurses self reported that providing psychosocial care was a fundamental nursing activity that defined nursing and the role of the nurse. Nurses' narratives indicated the need for a more specific definition of psychosocial care that better synthesizes with the provider role implied in the clinical guidelines. Nurses also cited further barriers to psychosocial care and suggested and designed a psychosocial care reminder project. Further, this data revealed that a key understanding to increased systematic involvement of nurses in psychosocial care would be a greater emphasis being placed on the clinical significance of psychosocial care. I provide a detailed discussion of my interpretation of this and other findings in the following chapter 5.

# Chapter 5: Summary, Conclusion, and Recommendations

## Overview

The purpose of this focus group study was to identify nurses' role beliefs and determine if these beliefs were a barrier to psychosocial care for patients with cancer. Previous barriers research rested on the assumption that nurses would provide psychosocial care for patients with cancer but there was a dearth of literature on nurses' role beliefs with respect to providing psychosocial care. A purposeful multinational sample of 10 nurses experienced in transcultural nursing discussed prior research findings on psychological distress and what these nurses believed to be their role in caring for patients with cancer, whether they believed nurses have a role in providing psychosocial care for patients with cancer, and what it would take for nurses to play a greater role in psychosocial care for patients with cancer. The data revealed that all nurses in this multinational sample steadfastly maintained that psychosocial care distinguishes the nurse's role from the physician's role; psychosocial care is a fundamental nursing activity. With qualification, nurses confirmed earlier research findings on barriers to psychosocial care and suggested further barriers. Nurses also stated that psychosocial care should be culturally congruent and following a suggestion for a reminder project designed one such project for psychosocial care (Appendix E). Finally, nurse narratives revealed that nurse knowledge of the clinical significance of psychosocial care is likely the key to increasing nurse involvement in psychosocial care for patients with cancer. In the following paragraphs I provide a discussion of key findings and my conclusions drawn from this study, recommendations and reflections of this study, and a brief conclusion.

## Nurses' Role Beliefs

The first question addressed what nurses believe to be their role for caring for patients with cancer. It also offered nurses' perceptions of the origins of their role beliefs and answered the question as to whether nurses believe they have a role in providing psychosocial care for patients with cancer. As one participant reported, "it's my job to keep people well, that's where I was coming from when I started nursing" (focus group 2). This finding also provided evidence that these nurses who originated from America, Japan, Lebanon, and Kenya all maintained throughout discussions that it is the role of the nurse to provide psychosocial care. These data revealed that the expectation that nurses would provide psychosocial care is reasonable in the absence of structural barriers. This finding emanated from the narratives of a multinational sample of nurses experienced in transcultural nursing, and carries positive implications for diverse nurse populations providing care in diverse patient populations.

## Concepts Within Psychosocial Care

Not surprisingly, the concepts of psychosocial care and how psychosocial care is defined would likely impact whether nurses define psychosocial care as an outcome of authentic nursing care or a "stand alone" nursing care intervention in line with the IOM (2006) definition, for example. In this study nurses' narratives regarding psychosocial care revealed powerful contradictions. On the one hand, nurses self-reported as "willing and capable providers" (focus group 1), yet they clearly deferred or acknowledged oftentimes avoiding psychosocial care due to psychological forces such as “personal reasons,” “lack of interest,” and “nurse motivation” (focus groups 1 and 2) and their descriptions of psychosocial care included “an area of nursing,” “going the extra mile,” or “going beyond,” which may be interpreted as going beyond physical care. Other abstract descriptions of psychosocial care included expressions such as “touchy feely nursing” and “handholding stuff” (focus groups 1 and 2). Also, fellow participants did not denounce these contradictions that indicated an unhelpful ambivalence towards psychosocial care although one nurse did state “we have to take ownership (of our psychosocial care)” (focus group 1). Nurses’ contradictions could also reflect their perceived disempowerment in the absence of support from nurse leaders, peers, and other health care professionals, aggravated by the lack of time barrier. Nursing has, after all, been a traditionally conservative discipline (Johnstone & Kanitsaki, 2008) so interpretations of disempowerment are plausible here. This interpretation also concurs with prior research on how role confirmation and role support makes for more confident nursing care practice (Haavardsholm & Naden, 2009). This finding may indicate that nurses here are focused more on the art of nursing than art and science of nursing, the former constituting moral pragmatic legitimacy in holistic role but not yet cognitive legitimacy which requires greater nurse involvement in systems that support the holistic role (Goodrick & Reay, 2010). Cognitive legitimacy arguably ties in with the evidence based clinical significance of psychosocial care discussed later herein. Holistic care has been defined as an ethical attitudinal approach to care (Strandberg, Ovhed, Borgquist, & Wilhelmsson, 2007), as opposed to care that emphasizes less than or non holistic care.

Nurses' contradictions may reflect hesitancy perhaps even "role abdication" (Pearcey, 2008, p. 1320) when it comes to holistic nursing care. It is, after all, highly unimaginable that nurses would use these same descriptions about the physical care they provide. This finding indicates the need for nurses to be educated about and move from the clinical significance of psychosocial care. The role of the clinical significance of psychosocial care offers a possibility for one overarching explanation for nurse contradictions and ambiguities and could be the solution to many structural barriers to psychosocial care. McFarland (2006) referred to care as "an elusive phenomenon" (p. 26) and to some extent we can likely expect no change here. However, nurses believing in the benefit to the patient of a given care behavior will more easily develop psychological power that will then drive innovative behavior, even in the absence of formal power (Knol & van Linge, 2009). Nurses have awareness, knowledge, skills, education, and the will essential for their physical care, despite structural barriers that invariably exist, especially the lack of time barrier. It is worth investigating to what degree and how these same constructs might play into psychosocial care. International cancer care networks are pulling nurses into integrated care but nurse leaders need to encourage and support other nurses more. In this study, psychosocial care was seen as a dimension of authentic nursing care. If psychosocial care is simply a dimension of holistic nursing care, then nurses need not feel anything less than legitimate providers of psychosocial care. Rather, according to these findings, nurses should advise their fellow nurses to "take ownership" of their nursing care.

## Barriers to Psychosocial Care

In this study nurses agreed with earlier barriers to psychosocial care but were seeking a more participatory approach to psychosocial care, mutuality, and relationships wherein their professional opinions are not subordinated, “we should be involved throughout” (focus groups 1 & 2) using a validated instrument to detect distress “so that we (nurses) could spend more time with the patient” (focus group 1). That these nurses felt the need to seek what is perceived as psychological permission to provide holistic nursing care is disturbing. Salhani and Coulter (2009) argued that a model of collaboration agreed upon by all participants is the only way to prevent “political micro struggles” for professional legitimacy in healthcare systems that share their ideologies (p. 1227). Nurses in this study further suggested a “big plan approach” (focus group 2) for patient care. Three nurses in this sample had direct personal or family experiences with cancer. Mortality awareness (Becker, 1997) heightened by personal experiences of existential crises may play a role in how insistent nurses are in finding ways to overcome barriers to psychosocial care, provide holistic care, and communicate along the lines of Herron’s “facilitative intervention” (Jack & Smith, 2007, p. 50), although patients’ needing to depend on nurses’ personal experience for care is unreasonable. According to Haavardsholm and Naden (2009), nurses’ own death reflection can make for easier communication with patients facing death. The “nurse motivation” and “personal stress” barriers to providing psychosocial care (focus groups 1 and 2) can be connected to nurses’ efforts to seek out further education, and efforts towards finding solutions to current barriers to psychosocial care. This finding was interpreted as quizzical because it questions the word *motivated.* Nurses claimed that providing psychosocial care defined their nursing role. Yet it is unclear how nurses need to feel motivated to provide such care even though they acknowledged it as a professional duty. Horton, Tschudin, and Forget (2007) explained that nursing has its professional roots in moral values because nursing is about caring, therefore nurse motivation may be connected to nurses being able, or in this case unable to “live out their moral values”; job satisfaction is negatively affected when nurses are unable to do so, suggesting the need for “nurses to be clear about what our nursing values are” (Horton et al., 2007, p. 725).

Interestingly, not all of the nurses in this study automatically accepted the personal stress and lack of education barriers cited in prior research and argued that “nurses lack of emotional resources and personal stress can’t be end of the line here…” (focus group 2) so too with education; “Education? There’s plenty out there” (focus group 2). This finding suggests an insistence on nurses’ self awareness; the individual nurse being asked to take responsibility for advancing her or his own learning; “physicians are not let off the hook; why should nurses be?” (Key respondent, personal communication, October, 2010). The education barrier was seen as a point of conflict for these nurses, resolved at the end of the discussions by nurses sharing educational resources. Optimistically, even if only one nurse refuted the claim for this lack of education barrier, refuting itself suggests the education barrier is not so firmly entrenched in nurses’ minds that it cannot be questioned, with good effect. The literature review for this work cited a number of resources available for nurses including free online courses for continuing education from the International Psycho Oncology Society (IPOS-society.org). Simply put, patient care depends on nurses keeping updated and wherever possible translating research findings into practice; nurse passivity cannot be helpful here. Recommendations for mandating continuing education across all areas of nursing to better ensure nurses can keep up with research findings outside their own specialty was suggested by these nurses and seen as an encouraging indication of nurses' capacity for problem solving, including seeking further education. However, the comment that "nurses need more education in psychology" before they provide psychosocial care because "I don't want to do anything wrong" (focus group 2) is a significant and helpful starting point for future research. This particular nurse participant later clarified that "we need more education at the undergraduate level then we can *expand* [emphasis added] through CE…now I can just listen, and I do just listen, but I don't want to do the wrong thing" (personal communication, December 16, 2010). This finding leads one to question nurses' perceptions of psychosocial care. Precisely, what image does psychosocial care portray for nurses and how does that image impact current practice? Nurses' perceived lack of confidence in providing psychosocial care, without further training or their lack of confidence that psychosocial care will actually help reduce distress, needs to be empirically explored. This finding ties in with nurses' being educated about the clinical significance of psychosocial care discussed later herein.

In this study systems of care was also discussed as a barrier to care with one nurse stating that "they don't want compassionate nurses…they want nurses who do the most and know the most, but." (focus group 1). Ironically, nurse evaluation systems themselves could be obstacles to care. Evaluation processes that pay lip service to authentic nursing practice while devaluing bedside nursing by “focusing on activity in other areas of nursing, such as being on this and that committee” (focus group 1) have implications for psychosocial care. First, when nurses feel they need permission to remain at the bedside one wonders how the nurse is expected to discover the patient’s worldview to better ensure culturally congruent care. Second, how is assessing or and monitoring for distress even possible unless the nurse is able to remain at the bedside? This question takes us to Lyons’s (1990) point regarding “nurses getting back on track” along with the need for nurse support tie in with nurse motivation and personal stress barriers. Gordon’s (2006) aptly titled book “Nursing Against the Odds” is duly and respectfully noted. The following excerpt clarifies the critical importance of bedside nursing and compassionate nurses:

> How might a care provider attend to a patient’s distress? …Intuitively, what might be done?...a care provider would take a seat at the bedside and begin to talk, or perhaps, listen…the provider’s presence holds tremendous therapeutic power; by taking a place at the bedside, whether asking questions about what matters, or listening to heartfelt disclosures the provider becomes the beholder. By listening to patients our perceptions of who they are extends beyond the confines of their illness, thereby shifting the patient’s perception of how they are seen and heard…validation of their concerns…can bolster hope…the reflection that patients see themselves in the eye of the care provider must ultimately affirm their sense of dignity. (Chochinov, 2004, p. 1138)

Also cited as barriers was the lack of accountability and monitoring for distress evident in the statement made by one nurse participants who asked: “Nurse’s notes? Do physicians read them anyway?” (focus group 2). This finding has far-reaching implications for individual nurses, nursing educators, patient care indeed, including what it might suggest about nurses’ feeling confident that their opinions and or recommendations are heard and that their notes serve any real purpose. Other implications are linked with psychosocial care and distress. Discussion and referring out were amongst the most commonly cited behaviors in these nurse narratives but monitoring was examined, “ if the truth be known, we drop the monitoring part though don’t we?” (focus group 1). Conclusions to be drawn here center on monitoring systems that are dependent on documentation of psychosocial care, which this study revealed as lacking: “we don’t document psychosocial care and we never discuss patient’s psychological care in report.” (focus group 1). At best, nurses may note something about the patient’s *feeling and functioning* (Lyons, 2008) but the above perceived distrust that anyone would read actually nurses’ notes (focus group 1) is unfortunately perhaps a reality especially where there is so little time, also cited by these nurses. Nurses obviously need to rethink the purpose of their nursing notes, to state the obvious here. In fairness however, one wonders how nurses can be expected to keep up in the absence of a system for monitoring and in a lack of time barrier context, It is difficult to imagine how monitoring might be able to take place under such circumstances but the implications for psychosocial care with respect to psychological distress are clearly evident. This study confirmed earlier research findings on the lack of documentation of psychosocial care (Gillan, 1994).

Nurses also noted the lack of any format for its documentation and suggested this could be a future project for nurses (focus group 2). One further possibility for a format or framework for psychosocial care and its documentation might be based on the holistic comfort theory that posits three types of comfort, “relief, ease, and transcendence within physical, psycho spiritual social, and environmental contexts” (Kolcaba & DiMarco, 2005, p. 46). Applying this theory to the findings in this study it could be argued that currently nurses may only be providing relief comfort and ease comfort in the physical and to some degree in the environmental contexts. Unless nurses are prepared to discuss the psychosocial needs their patients won’t be given the opportunity for Kolcaba’s *transcendence* comfort. Also, a grid of the four contexts and three types of comfort referred to as the taxonomic structure represents the holistic comfort that is considered the ultimate goal of nursing interventions (Kolcaba & DiMarco, 2005) does appear to offer a framework for psychosocial care and its subsequent documentation, which nevertheless requires health professionals “reading the notes” (focus group 1) in order to ensure “monitoring” for distress. This also indicates an avenue for future research. Summarily, a system of care that limits patient-nurse contact is an insidious barrier to authentic nursing. It is no exaggeration to make the claim that these systems can ultimately lead to perpetuating of patient suffering. If nurse leaders fail to make the association between authentic nursing, currently being shredded by sociopolitical factors, and poorly tended to psychosocial care or psychological distress, then it is difficult to imagine where nurses, and policy makers go from here, to the detriment of all.

## Differences in Hospital and Community Nurses' Experiences

This finding indicated that nurse leaders' support for nurses in this provider role would likely motivate nurses in hospital settings. Nurses working in the community likely have greater autonomy and independence thereby experience greater motivation towards holistic nursing care. This finding also suggests a role for community nurses in survivor care, including school nurses who could play a part in coordinating psychosocial care for students both during the immediate transitioning back into school, and beyond. Barriers experienced by these hospital nurses were mostly centered on systems of care in America when they stated, "insurance companies have too much power…and limit patient nurse contact" (focus group 2). This finding ties in with the Schroeder (2003) article about the "tyranny of profit" (p.173), how corporatized health systems move from a big business paradigm, and how its profit driven influence is carried over to health care delivery and the health outcomes of the populace. Lee and Rock (2009) also argued that medical health systems need to consider the biopsychosocial approach given the circularity of medical needs and psychosocial needs including long term care. It is reasonable to assume that such circumstances have serious implications for psychosocial care and psychological distress; "we will see them back in with pain" (focus group 1).

## Multinational Sample of Nurses

These nurses placed considerable emphasis on the importance of nurses knowing about the patient's culture, literacy, religion, and spirituality, as evidenced in statements such as "we must know the background before we can know how and what to co-ordinate" (America, Lebanon, Kenya) and secondly, "what am I going to educate an 80 years old man from in my village/country?" (Kenya). Optimistically, this finding can be said to reflect progress in culturally competent care (Coenen, Doorenbos, & Wilson, 2007; Torsvik & Hedlund, 2008). This finding suggests respect and need for heightened awareness for cultural perspectives on illness and nursing care and did not confirm the findings of Johnstone and Kanistaki (2008) who found that nurses too often lacked tolerance for cultural diversity amongst their patients. The nurses in the Johnstone and Kanistaki study included ethnically diverse nurses who originated from minority groups but according to the authors had apparently taken on the social expectations of the dominant group. In contrast, the nurses in this present study had all experienced living and working in a second or third culture in a second or third language as they moved between the minority and dominant groups; complex personal backgrounds might have cultivated their heightened awareness and concern for "culturally congruent care" (Leininger, 2002). This finding did concur with the position that people's worldviews are critical forces in health and wellness given that they influence the way we think about health and illness and care (Lovering, 2006; Shahid & Thompson, 2009). As the author of the expression *culturally congruent care* Leininger (2002) maintained that ethnocentric nursing may lead to misdiagnosis and be ineffective in promoting health and wellness; accurate nursing care planning can only take place once the meaning of care for that patient and his or her group has been clarified (Leininger, 2002; McFarland, 2006, p. 480). This would include nurses being cognizant of cultural differences in communication styles and diagnosis disclosure, "less than 50% of patients in Japan may know their diagnosis" (focus group 2) a finding that confirms an earlier point about the earlier cited “unspoken communication” considered protective of the patient (Powell, 2006). Lundberg, Backstrom and Widen (2005) have suggested that cultural diversity should not be an isolated subject in the nursing curriculum. Rather, nurses should be educated to apply the theory of culturally responsive care to all areas in nursing. Also, culturally congruent care should guard against perpetuating stereotypes that over-ride the individual patient (Triandis, 2000; Zoucha & Husted, 2000). The International Academic Nursing Alliance and the International Council of Nurses (ICN) both offer educational resources including international collaborative research (Senior, 2010) as does the nursing specialty area of transcultural nursing.

The finding that nurses from individualist and collectivist cultures indicated differences in approaches to psychosocial care while not surprising, was interesting. Despite perceived differences in approaches to psychosocial care all these nurses ended at the same point with regards to their claimed need for nurse monitoring; whether the individual patient be empowered or the family support be empowered. Theoretically, individual patient psychosocial needs could be obscured by either of these approaches unless every effort is made to ensure “patients should not have to do it alone” (focus group 2).

The multinational sample of nurses offered another interesting and important finding reflected in the comment made by one nurse during discussion on psychological distress: “they might go deeper into their religion” (focus group 2). Nurses from the Middle East and Africa both cited religion and spirituality beliefs and values amongst the needs of patients. A conclusion to be drawn from this finding cautions us against oversimplifying “fatalism talk” and “cancer fatalism” (Keeley, Wright, & Condit, 2009). Superficially, fatalism seems in contrast to the Western values of internal locus of control and self determination (Schwartz, 2000) but nurses are advised that fatalistic talk might better be seen as a coping response that gives illness meaning, and helps manage illness uncertainty for some patients (Keeley et al., 2009). This perspective also suggests that a person’s worldview may help prevent distress in some patients. With some patients for whom the cancer diagnosis is a “punishment from god” nurses stated that they “may never see the patients again” since patients may not return to the hospital for follow up medical care (Kenya and Lebanon). Nurses need to develop “true awareness,” of a patient’s worldview because it has implications for patient communication and follow up support (Lundberg, Backstrom, & Widen, 2005, p. 259). The advantages of the multinational sample of nurses were illustrated in these finding in that these nurses were able to learn and discuss, in real time, different perspectives on interpreting patient behavior including those that lay outside common Western cultural interpretations.

### Do Nurses Know the Clinical Significance of Psychosocial Care?

A theme that emerged from this data was the significance of psychosocial care. The importance and value of nurses knowing and basing their psychosocial care on its clinical significance; namely its capacity to address, treat and or prevent psychological distress was another major finding from this study and answered the third research question of this study what would it take for nurses to take on a greater role in psychosocial care? Motivation scholars Deci and Ryan (2008) referred to the “outcome value” (p. 16) of a given behavior. Applying this concept to psychosocial care, when nurses know the outcome value (significance) of providing psychosocial care, the value (preventive) is more readily internalized and integrated with other nursing values (alleviate patient suffering) and the individual nurse would then be motivated towards that behavior (Deci & Ryan, 2008). Nurses approaching psychosocial care from its evidence based clinical significance is argued as the key to increased nurse involvement in providing psychosocial care. To reiterate, this study did not seek a definition per se of psychosocial care. However, nurses' narratives described psychosocial care in highly varied subjectively defined terms and a noticeable mixture of attitudes and behavior all of which seemed to reflect the broad scope of nursing and or nursing philosophies. These descriptions did not indicate understanding or acknowledgement of the prevention of psychological distress (outcome value). In contrast, the psychosocial care based on the IOM (2006) statement is aimed at detection, diagnosis, treatment and prevention of psychological distress; all behaviors that imply intervention (Jack et al., 2007). This finding and the earlier finding on nurses' perceptions of the concepts of psychosocial care (Table 4) raises questions about the terminology or how to define psychosocial care; nurses must be sure that we are all speaking about the same thing, however elusive*,* if nurses expect patients to benefit from psychosocial care "we (nurses) don't have this term ('psychosocial care') in Japanese, maybe 'mental'? " (focus group 1). In this case, because the Japanese language has no literal translation of 'psychosocial care' nurses might use '"mental care" giving the impression that psychosocial care might be seen by some nurses as a separate area of expertise afterall. However, "mental care" was used interchangeably with "emotional care" for the Japanese nurses in this study and mental care assumed psychiatric care. Simply put, it is not difficult to imagine how the lack of clear and shared definition can lead to conflict about the scope of care. Although, all these nurses from America, Japan, Lebanon, and Kenya, did at some point in their narratives indicate that they perceived psychosocial care as a dimension of holistic nursing care rather than a separately bounded area of expertise, contradictions notwithstanding and further supporting themes of nurse hesitancy and nurse confusion. However, confusion in terms of the clinical significance of psychosocial care would be less likely when clinical significance is routinely addressed into the nursing curriculum, albeit an already full curriculum with its own challenges. Education about the clinical significance of psychosocial care and its application can surely be done however. According to one participant, the essence of psychosocial care is "engagement and letting the patient that they don't have to do it alone" (focus group 2) and the clinical significance of psychosocial care is science-based prevention of prolonged suffering. As mentioned earlier these concepts may be one and the same thing but this study's data suggests they need to be better synthesized.

## Social Change

As a result of this study, it is argued that positive social change has begun as illustrated in the following excerpt of the focus group discussion as participants discussed the final research question: What would it take for nurses and greater involvement in psychosocial care?

> P3: Top-down…nurse leaders…it's like hand washing…that came from the top down didn't it? (Imitating) *"Did you wash you hands?"*…We could do the same

> thing for psychosocial care, "Did you *talk* [emphasis added] to your patients today?" (group laughter).

The nurse participant who suggested this solution referred to this as a "sit-and-pause" project "Have You *Talked* to Your Patient Today… Nurses and Psychosocial Care." The initiator nurse participant has since arranged for a colleague to draw up the reminder poster with the idea of distribution to nurses working in local clinics, hospitals, and schools. Other nurse participants from this multinational sample who participated in this study translated the message from English into different languages that currently include Arabic, French, German, Hebrew, Japanese, and Swahili. Although still in its embryonic stages, this project is reportedly in progress (Appendix E). This reminder project also signifies nurses' capacity to problem-solve and illustrated the capacity for the co-construction of knowledge through using the focus group method (Wibeck et al., 2007), and links with research that cited that reminders might help health care providers establish a routine for psychosocial care (Schofield et al., 2006).

It is reasonable to claim that the psychosocial care reminder project initiated by a nurse participant who later collaborated with others to implement this reminder into daily nursing care practice could well be considered an innovation for positive social change. The implications for positive social change would include the melting away of any dilemma currently experienced by nurses as they juggle the current task orientated practice based on the medical model with those time honored values of nursing care. The reminder has practical value as well as essential connection to authentic nursing that centers on what the patient is feeling and how well he or she is functioning (Lyons, 1990). The reminder project moves the patient closer to integrated care designed at improving patient quality of life.

## Recommendations for Action and Further Research

In light of these findings, this researcher makes the recommendation for nurse educators and designers of nursing curriculum to direct nurses' clinical care practice so that is driven by the evidence based clinical significance of psychosocial care. This researcher also makes the recommendation for the International Council of Nurses (ICN) to promote the reminder project amongst its nurses.

The focus group method used in this study was able to emanate a hypothesis regarding the clinical significance of psychosocial care, thus offers a focus for further research that could include both interventional research as well as observational research. One of the nurse participants in this current study asked, "statistically speaking, how many nurses are aware that this (providing psychosocial care in accordance with the clinical guidelines) is part of their role?" (focus group 1). Quantitative research carries the advantage of increasing the current knowledge base about psychological distress, psychosocial care for patients with cancer, and barriers research. The findings of this research elicit the theory of reasoned action (Fishbein & Ajzen, 2005) and the theory of planned behavior (Ajzen, 1991), theories that are used in health psychology research and could also frame future research projects. Future research could also focus on defining psychosocial care more concisely so that it may be shared globally amongst nurses and other health care professionals. One nurse participant in this present study suggested designing a format for documenting of psychosocial care. This could also be an area for future research.

## Reflexive Statement

These findings are an understanding of how this researcher made sense of this data (Bloomberg & Volpe, 2008). Originally, I made five assumptions with respect to nurses' role beliefs and providing psychosocial care. The first assumption was that there would be lack of consensus about the role of the nurse. This assumption was not supported by the data. The assumption that nurses would make no distinction between comfort care and psychosocial care was supported. There was consensus on the concepts within psychosocial care, that psychosocial care was part of holistic nursing care and nurses were clear and insistent that providing psychosocial care was the role of the nurse. The second assumption that nurses would expect hospital leaders alone to be responsible for structural changes was supported by the data as was the assumption that community nurses would have an easier time than hospital setting nurses at providing psychosocial care, primarily due perhaps to greater nurse autonomy outside the structured hospital setting. The assumption that nurses would see themselves as lacking accountability was partially supported by the data. Nurses did see themselves as accountable for all nursing care in a moral sense, but acknowledged the "system" did not demand concrete practical accountability and further claimed that this factor is a hindrance that contributed to nurses' avoiding psychosocial care because it blocked holistic authentic nursing care, and subsequently leading to nurse hesitancy. The assumption that psychosocial care was an outcome of good nursing care rather than an intervention was partially supported. Some nurses described psychosocial care as “going beyond” (focus group 1) which, presumably meant going beyond physical care and implicitly meaning that psychosocial care was one dimension of overall nursing care, while yet another nurse described psychosocial care as coordinating patients’ needs (focus group 2). Authentic nursing care necessarily includes psychosocial care, according to these participants. At the same time, nurses’ narratives were self-contradictory. The definition of psychosocial care was outside the boundaries of this study but this finding indicates the need for further research on this topic, ideally in the near future. Finally, the assumption based on Lazarus’s (1991) cognitive motivational relational theory of stress and emotion whereby nurses might avoid psychosocial care because the provider role was unclear, was only partially supported and in hindsight, oversimplified. Personal stress and lack of emotional resources were both cited by nurse participants as reasons why nurses might not provide psychosocial care but they were not explored in detail in the discussions. Initially, this researcher assumed that avoidance of psychosocial care for patients with cancer would be connected to nurses’ role beliefs and the existential nature of the cancer diagnosis. The actual findings were both broader and deeper however. Nurses’ role was clarified empirically, as this was the essential gap. Nurses were adamant throughout that providing psychosocial care belonged in the nurses’ role for any and all diagnoses, including cancer. Nurses simply needed leader and other health care professionals’ support in this role because the lack of time built its own context that determined care, including the quality of care, and whether nurses could “go beyond” physical care to find time to talk to their patients. Lazarus’s (1991) theory more likely makes its entrance at the point related to the person environment relations with respect to nurse education concerning “the clinical significance” of psychosocial care as opposed to their role beliefs. The role beliefs of the nurses in this study were not determined as a barrier to psychosocial care.

In retrospect, these nurses were all experienced in transcultural nursing but adding a demographic question about formal education on transcultural nursing would likely have provided a fuller picture of this multicultural sample. Finally, would-be researchers are told that data validity, trustworthiness, and being faithful to the data are all essential to rigorous and helpful research. As a result of this research process I came to see these as helpful anchors that can provide the researcher with confidence in the data analysis process and its results.

## Conclusion

This study added to the existing knowledge on barriers to psychosocial care. In this focus group study that empirically identified nurses’ role beliefs, nurses claimed that providing psychosocial care is within the role of the nurse. Nevertheless, this finding does not allay concerns that some nurses’ psychosocial care may fail to facilitate the detection, diagnosis, treatment and or prevention of psychological distress. My analysis of the data leads me to conclude that nurses providing psychosocial care along the lines of those stated by international cancer care networks (NHMRC, 2003; IOM, 2006; NCCN, 2007) is not something patients or policy makers can rely on at this time. Nurse educators are urged to take the necessary steps to correct this knowledge gap given that patients are currently being asked to bear its burden.

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# Appendix A: Informed Consent

You are invited to take part in a research study of the role of nurses and psychosocial care. You were chosen for the study because you are a nurse of more than 6 months nursing experience. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part. Kerry Suzuki who is a fellow nurse and a doctoral student at Walden University, Mn. USA, is conducting this study.

**Background Information:**

The purpose of this study is to identify what nurses believe is their role in the care for patients with cancer. I am interested in hearing your ideas about the role of the nurse.

**Procedures:**

If you agree to be in this study, you will be asked to:

. Be available for 2 hours with 90 minutes for discussions on the role of the nurse.

. Fill out a demographic sheet.

. Answer one dichotomous survey question regarding psychosocial care and the role of the nurse.

**Voluntary Nature of the Study:**

Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No one at nursing network or your workplace will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind during the study. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal.

**Risks and Benefits of Being in the Study:**

Except for your time and inconvenience there are no risks to your participating in this focus group discussion. As nurses we are all likely touched by cancer professionally or personally or both and while there may be no direct benefits to you by participating in this focus group, this research may offer an opportunity for nurses to discuss the need for systematic psychosocial care in patients with cancer and the role of the nurse. As to the wider community benefits, this study could result in greater nurse attention to and involvement in psychosocial care for patients with serious illness the likes of cancer. In the event that you experience stress or anxiety during your participation in the study you may terminate your participation at any time.

**Compensation:**

There is no compensation for your participation in this study.

**Confidentiality and Anonymity:**

Any information you provide will be kept confidential. I will ask all participants to keep these discussions confidential. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study. All records will be kept locked in the researcher's office and or kept password protected and personally shredded after 5 years.

**Contacts and Questions:**

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via telephone 81.3.3704.0527 and or email at ksuzuki@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Contact telephone number 001- 612-312-1210. Walden University's approval number for this study is **06-10-10- 0074755** and it expires on **June 9, 2011.**

The researcher will give you a copy of this form to keep. There are no conflicts of interest.

**Statement of Consent:**

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. I agree to the terms described above.

Printed Name of Participant: Date of consent: Participant's Written or Electronic* Signature:

Researcher's Written or Electronic*: Signature: * Adapted from Walden University Template.

# Appendix B: Sample of Field Notes on Group Interaction

CONSIDERATIONS
**GROUP #1**
**GROUP #2**

How closely did the group adhere to the issues presented for discussion?
Did not go off track frequently. In-house jokes but back on track quickly.

Very close: Perhaps because they knew in advance that they only had 90 minutes to complete the discussions, so there was a "task" to undertake. Have no impression of them going off task. If the explanations were long then the speaker invariably circled back to the issue under discussion.

Why, how and when were related issues brought up?

Because the stimulus materials were used for the discussions these were uncovered when the topic was mentioned in the conversations. Barriers, systems, and resources were raised; limitations to realistic expectations for psychosocial care.

Culture was brought up very early on. Respect for complexities and caution against oversimplifying psychosocial care. All seemed to agree on this point.

What statements seemed to evoke conflict?

Ideal nursing care opposed to "reality" re current nursing practice

Patient Education. Timing for patient education.

What were the contradictions in the discussion?

One nurses answered "unsure" on the survey but in the discussions responded differently. He said that yes, it is our role and we are "willing and capable of providing psychosocial care…" Based on this comment and other comments about his experience during the discussions my guess is that he was confused about the wording/definition, perhaps? (Key Respondent #1)

All nurses said yes, it was their role to provide psychosocial care yet admitted that nurses didn't always do it. They admitted that nurses might avoid psychosocial care "because it is stressful, but … even though we know we have to do it…"

What common experiences were expressed?

Rushed care. Unsupported nurses.

Cultural diversity… nursing in settings that required shifting approach i.e. be aware of cultural backgrounds that were different from nurse's own background.

Were alliances formed among group members?

Not evident

Not evident

Was a particular member or viewpoint silenced?

No perception of member silencing.

Not member-silencing but viewpoint on personal stress as a reason for not providing psychosocial care.

Was a particular view dominant?

Yes, the view that US system of care is essentially incongruent with holistic nursing care.

Yes. The view that nurses *must* make efforts to know patient context. Context includes culture, personality, family, religion, education, and understanding of their illness.

How did the group resolve disagreement?

There was no perception of obvious disagreement in this group.

(Table continues)

Used a particular expression - For example, "I would just like to add to your point on… " Then offer another perspective, citing relevant experience. Also, tried to get a bigger picture by including the context, then verbalized this… i.e. P5 discussion about P3 combined medical and nursing and her emphasis on patient education.

What topics produced consensus?

US systems of care in which nurses are unable to refer out. They would need to go through the GP who may or may not follow up on the nurse's recommendation. Also, in the US system of care other health professionals wouldn't support the nurse as a provider unless nurse leaders made it clear, formal, and possible. Nurse leaders are invisible… need for top-down involvement. *"... validated tool would allow nurses to take the time without criticism from others, including peers, when care is spent on the type of care that is more abstract than physical care" (FG!P3).* Nurse as a provider of psychosocial care. ALL health care professionals should provide psychosocial care for patients with cancer. Provider role domains overlap.

Providing psychosocial care is within the domain of the nurse. It is part of the nurse's role to provide psychosocial care to all patients. Nurses should be involved all the way through. Team approach to cancer care can best ensure follow-up. Theme of "nurse involvement throughout" emerged early.

Whose interests were being represented in the group?

Nurses. Although fellow nurses who did *not* provide psychosocial care were reproached.

Nurses. Reproached fellow nurses who avoided psychosocial care BUT qualified this with "personal stress".

How were emotions handled?

Altered voice pitch. Laughter. In-house jokes.

Laughter, joking, compliments, increased the speed of speech delivery, silence.

Evidence of "collectivism"?*

Yes.

Yes.

Evidence of raised awareness? *

Yes. Raised awareness of Psychological Distress. Interest in validated tool. Took notes about IPOS and Distress Thermometer after the recordings were switched off.

Yes. Raised awareness, interest, and suggested concrete plans for improving psychosocial care. Took notes about IPOS after discussion, and via emails.

- Questions/considerations adapted from scholarly literature (Stevens, 1996; Webb & Kevern, 2001; Wibeck, Abrandt Dahlgren, & Oberg, 2007).

# Appendix C: Framework for Key Codes in Data Analysis

Psychosocial Care, and NRB (before discussion).
FG 1
FG2
Exceptions
Psychosocial Care, and NRB (after FG discussion).
FG1
FG2
Exceptions
Perceptions of Psychosocial Care (image)
IFG2
IFG2
Exceptions
Impressions of structural barriers to providing psychosocial care (time, skills, education).
FG1BI
FG2BI
Exceptions
Psychological forces as covert barriers (communication, stressful)
FG1CB1
FG2CB2
Exceptions
Perceptions of provider role (domain-nurse, social worker, mental health)
FG1PROLE1
FG2PROLE2
Perceptions of origins of NRB (social expectations, education, experience)
FG1RORIG1
FG2RORIG2
Psychosocial care is an intervention or outcome of 'good nursing care'?
FG1IoO1
FG2IoO2
Exceptions
Diagnosis and psychosocial care (cancer, existential illness)
FG1CANREL1
FG2CANREL2
Exceptions
Perceptions of what it takes for nurses & greater role (training, support, hierarchy).
FG1NGROLE1
FG2NGROLE2
Perceptions of how patients' psychosocial care needs might be met (what's next?)
FG1PHMET1
FG2PHMET2
Perceptions of need for training before providing psychosocial care (training is an ethical requirement before nurses provide psychosocial care).
FG1TER1
FG2TER2

Exceptions

# Appendix D: Sample Field Notes Post Discussions

| Information | Focus Group 1 | Focus Group 2 |
|---|---|---|
| Date | July 1, 2010 | July 3, 2010 |
| Site | Classroom,<br>Japan. | Classroom<br>Japan. |
| Duration | 90 minutes recording | 90 minutes recording |
| Gender | Female n=3<br>Male n=2 | Female n=5<br>Male n=0 |
| Group Atmosphere<br>Overall Impressions | Lively. Appeared pleased to be participating. Curious about research. Quick to enter discussions, laughter, jokes, but took questions seriously, remained on task, respectful of one another, no perception of dominance, everyone gave opinions throughout. Communicative. Cited experiences. Opinions converged but went up and back. In agreement on the role of the nurse. Answered all research questions. | Friendly. Appeared pleased to be participating. Sociable. Discussions quiet at first. Looked a bit puzzled. Why? Reflexive: What did these questioning faces indicate? *"…but of course…why are you asking this?"* OR *"you are not being clear in what do you want from us here?"* (check with audio recordings). On task throughout. Dominance not a factor. Collaborated re practical solutions. Answered all research questions. |
| Recording Technology | 3 audio recorders. Assistant present throughout. | 3 recorders. Assistant present throughout. |
| Other equipment | Desks, chalkboard, writing materials, snacks, bottled water, flowers. air conditioning. | Desks, chalkboard, writing materials, snacks, bottled water, flowers, air conditioning. |

# Appendix E: Reminder Project. Social Change Initiative

Have you *talked* with your patients today?

…Nurses and Psychosocial Care…

*Author: Nurse Participant.
Languages: Arabic, English, French, German, Hebrew, Japanese, and Swahili.

# Curriculum vitae

## Academic Experience:

| | |
|---|---|
| 2005-Present | Candidate for Doctor of Philosophy Health Psychology Walden University, Minneapolis, Minnesota, USA |
| 2005 | M.A. Health Psychology Walden University, Minneapolis, Minnesota, USA |
| 2002 | Graduate Certificate of Adolescent Health & Welfare. Melbourne University, Victoria, Australia |
| 2000 | B.A. Health Psychology Stephen's College, Missouri, USA |
| 1983 | Registered Nurse. Box Hill Hospital, Box Hill, Victoria, Australia |

## Relevant Professional Experience:

| | |
|---|---|
| 1985-Present | School Nurse (full time) [redacted] Japan |

Responsible for conducting health program for students from KG to 12th grade levels including physical screenings, environmental safety, public health, children with special biopsychosocial health needs, staff annual checks, collaborating with community medical and psychological health resources, child and adolescent treatment planning, and provide contributions to the health and development curriculum. Stress management classes for individual adolescents and children, and adult staff. Stress management for matriculating senior students.

## Community Service Experience:

| | |
|---|---|
| 1985-Present | Volunteer nurse at local community activities<br>Volunteer First-Aid-CPR classes<br>Language interpreting for non-Japanese speaking patients at local clinics /hospitals |

## Licensure and Certifications:

Registered Nurse, State of Victoria, Australia
Received October 19, 1983. License # 90136

Professional Organizations:

Royal College of Nursing, Australia (RCNA)
International Council of Nurses (ICN)
Foreign Nurses Association, Japan (FNAJ)
Transcultural Nursing Society
International Psycho-Oncology Society (IPOS)

Research Interests:

Illness related stress and coping
Transcultural Nursing.