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Jessica Moore Begans

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Jessica Begans
Measuring the Cultural Competence of
Hospice Social Workers Using the
Multicultural Counseling Self-Efficacy
Scale – Racial Diversity Form, Revised
Version, for Use in Hospice Settings

ABSTRACT

Although about 40% of American deaths occur in hospice care, and although social workers are members of nearly all hospice teams, there is scant research on the cross-cultural practices and competence of hospice social workers. Before this study, no self-report cultural competence scale was available to measure the perceived cultural competence skills of hospice social workers. To address this issue, a validated cross-cultural competence scale, the Multicultural Counseling Self-Efficacy Scale – Racial Diversity (Sheu, 2005) was modified to reflect the functions of hospice social workers. The revised scale (Begans, 2011) was completed by 33 hospice social workers in a New England state. Cronbach's alpha was used to examine the internal consistency of the revised scale; results indicate that the revised scale is highly reliable (37 items; $\alpha = .973$), suggesting that items were tapping similar constructs. Subscale alphas were similarly robust. The revised scale is suitable for use in medical and hospice settings where end of life issues predominate.

The surveyed hospice social workers rated their skills in working with cross-cultural and cross-racial hospice clients highly overall, a finding which had not been expected based on the literature review. The research and practice implications of the findings are discussed in detail. It is hoped the results will be of interest to hospice, palliative care and medical social workers, and will add to the conversation and research about culturally competent care at the end of life.

MEASURING THE CULTURAL COMPETENCE OF HOSPICE SOCIAL WORKERS USING
THE MULTICULTURAL COUNSELING SELF-EFFICACY SCALE – RACIAL DIVERSITY
FORM, REVISED VERSION, FOR USE IN HOSPICE SETTINGS

A project based upon an independent investigation, submitted in
partial fulfillment of the requirements for the degree of Master of
Social Work.

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2011

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CHAPTER I

Introduction

The aim of this exploratory study was to examine the practice of hospice social workers, with particular reference to how this group describes their skills in working with cross-racial and cross cultural clients. To accomplish this goal, the Multicultural Counseling Self-Efficacy Scale – Racial Difference (Sheu, 2005) was adapted, with the author’s permission, to tap elements of cross-cultural practice unique to end-of-life work. The modified 37-item Likert-type questionnaire was piloted with 33 Masters level social workers practicing in New England.

Hospice is a growing form of end-of-life care in the United States; over 40% of American deaths occur in hospice (NHPCO, 2010a). Racial and ethnic minorities do not access hospice care at the same rates as whites (Elioff, 2003; NHPCO, 2010a); researchers have identified institutional (Reese, Melton & Ciaravino, 2004) and cultural (Reese, Ahern, Nair, O’Faire, & Warren, 1999) barriers that are, in part, responsible for this difference. In addition, the rich literature from medicine, anthropology, sociology and other social sciences demonstrates that illness, dying, death and grief are all culturally-bound and must be understood through the lens of culture.

Social work is an essential service in hospice care; hospice agencies seeking Medicare funding are now required to have social workers on their staff (Hospice Care, 2000). Hospice social workers visit patients in their homes and perform psychosocial assessment, case management, psychotherapy and family counseling, and some facilitate bereavement counseling and groups. The literature is silent about how social workers perform all of these functions when

working with a client of a different race or ethnicity from themselves. One important early study elicited written narratives from hospice social workers about their “most perplexing or confusing experience” (Wesley, Tunney & Duncan, 2004). The thematic response of the majority of social workers who participated (31 of 32) indicated that these hospice social workers felt “inadequate to meet the needs of patients whose ethnic, religious or spiritual traditions were unfamiliar to them” (p. 43), suggesting that cross-cultural counseling can be an important and difficult task for hospice social workers.

The NASW Code of Ethics calls for social workers to educate themselves and continue to improve their cross-cultural practice (NASW, 2008). Hospice is a growing institution in healthcare that touches the lives of millions of patients and family members each year.

The purpose of this small study, then, was to address a gap in our research tools by adapting a well thought out and validated measure of cross-racial practice competency, the Multicultural Counseling Self-Efficacy Scale – Racial Diversity (MCSES-RD), for use in the end of life setting. Through this effort my aim was to pilot the revised tool and learn more about how one clinical sample of hospice social workers view their cross-cultural practice and competence. It is hoped the results will be of interest to hospice, palliative care and medical social workers, and that it adds to the conversation and research about culturally competent care at the end of life within the social work profession.

CHAPTER II

Literature Review

This literature review comprises three major sections bound by this introduction and a summary. It begins by discusses the history and current scope of hospice care. The next section reviews literature on the role of social workers on the interdisciplinary hospice team. The third section concludes with a detailed look at the meaning and history of the concept of cultural competence, and cross-cultural issues that may arise in hospice social work settings.

History of the Hospice Movement

Although hospice originated fewer than 50 years ago, humans have been dying, caring for the dying and trying to make meaning out of death since time began. The first “hospices” were refuges for the poor and sick, run by the Catholic Church in medieval Europe (Wolfensberger & Thomas, 2009). Care for the ill was originally the purview of spiritual leaders throughout the world (Pierson, 2000). Advances in antibiotics and medical and surgical procedures meant that fewer people died from infections and traumatic conditions, and more lived with and died from chronic conditions (Pierson, 2000). As societies became urban and industrialized, hospitals became centers of medical care, especially for chronic and terminal diseases, where doctors could attend to many patients under the same roof.

The first modern hospice was created by Dame Cicely Saunders, who founded St. Christopher’s Hospice in a London suburb in 1967 (Barker, 2005). Over the course of her long career, Saunders trained as a nurse, then as an almoner (a profession we would now call a medical social worker) (Clark, 2001), and then became a doctor (Barker, 2005). She was a one-

woman interdisciplinary team! In 1948, while working as a hospital nurse, Saunders fell in love with a patient, a Polish, Jewish immigrant waiter dying of cancer. He left her £500 to found a new sort of home for people in his condition – in pain and dying – telling her, “I’ll be a window in your home” (Clark, 2001). In the following years, Saunders worked at St. Luke’s Home of the Dying Poor. After receiving her medical degree, she researched pain at a Catholic hospice serving the poor, where she fell in love with another patient who died (Barker, 2005).

In 1963, during the beginning of the fundraising process for her own hospice, Saunders shared her vision for a new kind of end-of-life care at Yale School of Nursing in 1963. Social workers, along with nurses, physicians, chaplains and others, were in attendance at her lecture (National Hospice and Palliative Care Organization, 2010b). This lecture led to a long collaboration between Saunders and the Dean of Yale School of Nursing, Florence Wald. The founding of St. Christopher’s Hospice, the first hospice in England and the world, was influenced, at least in part, by Saunders’ Christian faith (Barker, 2005). In 1968, Wald took a year-long sabbatical to visit St. Christopher’s hospice and learn about this new model of care (NHPCO, 2010b).

Clark (2001) makes use of personal correspondence between Saunders and her close associates to learn more about the religious ideas behind St. Christopher’s Hospice. Clark describes Saunders as an evangelical Anglican. When Saunders considered the goals of her new kind of medical care, she struggled with the question of what role religion would play. Ultimately, Saunders decided against locating hospice strictly within the evangelical arm of the Anglican Church, and also against creating hospice as a new kind of religious “community” to be run and ministered only by members of the community, with the goal of preaching to and converting patients before their deaths. Instead, she collaborated with peoples from a wide range

of religious faiths, including many Jewish clinicians in America. But hospice was never a strictly medical concept for Saunders, whose concept of “total pain” took into account suffering caused by physical, mental, emotional, spiritual and social ailments (Clark, 2001). Saunders (cited in Clark, 2001) explained the balance between her point of view as a spiritual person and her point of view as a physician:

[I]n this work the medical and spiritual are inextricably mingled. I long to bring patients to know the Lord and to do something towards helping many of them to hear of him before they die, but I also long to raise standards of terminal care throughout the country from a medical point of view at least, even where I can do nothing about the spiritual part of the work (cited in Clark, 2001, p. 356).

The influence of Elisabeth Kubler-Ross

Another crucial moment in the history of hospice was in 1969, with the publication of Dr. Kubler-Ross, a psychiatrist, interviewed terminally ill patients and wrote about the stages of grief she observed in them as they approached their own deaths. Kubler-Ross wrote that the American culture, especially medical culture, isolated the frail and dying out of a need to avoid thinking about death, to the detriment of those experiencing the dying process and those around them. “Early in my work with dying patients I observed the desperate need of the hospital staff to deny the existence of terminally ill patients on their ward” (1969, p. 251). Kubler-Ross found the “paternalistic” medical culture demeaning to patients: “When a patient is severely ill, he is often treated like a person with no right to an opinion” (1969, p. 22) and advocated for greater sensitivity and respect for dying persons. *On Death and Dying* became a best-seller, and the book’s ideas were widely discussed in the media and remain well-known today. An article in

Time magazine stated that 42 years after its original publication: “the five stages of grief are so deeply embedded in our culture that they've become virtually inescapable” (Konigsberg, 2011).

Legislation

The first hospice in the United States, Connecticut Hospice, opened in 1974, followed soon by a few additional hospices in other parts of the country (Hospice of Michigan, 2010). The National Hospice and Palliative Care Organization was founded in 1978. In 1979, the Health Care Finance Act funded 26 new hospice programs around the country to study the cost-effectiveness of end-of-life hospice care and to determine which treatment and service options would combine to become standardized as “hospice” (NHPCO, 2010b). In 1982 the Medicare hospice benefit was created as a provision in the Tax Equity and Fiscal Responsibility Act, which dictated the guidelines under which hospice agencies could file for reimbursement from Medicare. The benefit was made permanent by legislation in 1986 (NHPCO, 2010b). Since then, many states have also included hospice benefits in Medicaid.

Nature of hospice care

The care provided by hospice is palliative, not curative. Palliative care improves the quality of life for patients “facing the problems associated with life-threatening illness, through the prevention and relief of suffering of early identification, and impeccable assessment and treatment of pain and other problems, psychosocial and spiritual” (World Health Organization, 2003). In addition, palliative care:

provides relief from pain and other distressing symptoms...intends neither to hasten or postpone death;... offers a support system to help the family cope during the patients illness and in their own bereavement;...uses a team approach to address the needs of patients and their families, including

bereavement counseling, if indicated;... [and] will enhance quality of life, and may also positively influence the course of illness (World Health Organization, 2003).

Currently, hospices operate all across the United States. Hospice teams visit patients in their homes, whether home is a house or a nursing home, and some hospices offer residential treatment.

Hospice utilization

The number of people who die in hospice grows every year. 41% of all deaths occurred in hospice in the United States in 2009. That year, over one million people died in hospice, with another 294,000 who remained in the hospice census at the end of 2009. Around 243,000 patients were discharged from hospice alive due to extended prognosis, desire for curative treatments, or other reasons. All together, an estimated 1.56 million patients received treatment from hospice in 2009 (NHPCO, 2010), and this number does not account for the family members who engaged in the hospice process as well. As more and more people choose to die in hospice, as more families are affected by its policies, as more social workers are employed to work with this population, the more necessary it becomes to study the needs of this hospice population and the interventions best suited to this work.

The Role of Social Workers on Hospice Teams

Reese and Raymer write that, “Unfortunately, the social work profession has been slow to measure empirically its contribution to hospice and palliative care” (2004, p. 417). However, literature does exist in the form of narratives and empirical studies on the evolving role of social workers on hospice teams.

End-of-life social work before the hospice movement

Hospice social work grew out of medical social work, and in both settings, issues of illness and death are paramount. The prevailing beliefs around death have changed dramatically in the medical community over the past several decades. For example, the ideas around disclosure of terminal illness have changed. For example, the research of Novack, Plumer, Smith, Ochitill, Morrow, & Bennett (1979, as cited in Candib, 2002) indicated that in 1961, the majority of physicians did not reveal cancer diagnoses to their patients directly, but by 1977, 98% of physicians said it was their policy to disclose cancer diagnoses directly to affected patients.

Foster & Davidson (2003), two social workers who worked with dying patients for several decades, explain, using their own practice knowledge, the role of the medical social worker within the context of the history of the American medical establishment's treatment of death and dying in the decades before the hospice movement. Foster describes her memories of being an inexperienced worker on the lymphoma ward and experiencing the "culture of silence" (p. 314) around dying in the 1960s. The authors write that "beneath the silence were turmoil and chaos; the terror of nightmares" (Foster & Davidson, 2003). This social worker senses that the patients feel abandoned and terrified as they face death without being able to discuss it openly with their family and physicians. In her experience, doctors withheld information about a patient's terminal prognosis. By withholding information, doctors thus maintained an authoritarian relationship with their patients, in which the patients did not know enough about their diagnosis to ask questions, lobby for treatments, etc. The authors then chart how this aspect of medical culture changed so that physicians now prefer to tell their patients openly their diagnosis and prognosis (Foster & Davidson, 2003). The authors also write that this culture of

silence affected clinicians, who were required to maintain “professional distance” even though they were also experiencing fear around death. The authors write that one of the benefits to the hospice movement and the writings of Elisabeth Kubler Ross was that it allowed medical culture to “place value on emotional openness and sensitivity” (Foster & Davidson, 2003, p. 314).

Foster & Davidson,, both social workers, do not discuss issues around the treatment of death in cultures other than mainstream American. They welcome the more open atmosphere of current physicians, denoting that openness, honesty and the patient as the locus of control over medical decisions is the best policy. The author's view, as social workers, is that a reluctance to talk about death is evidence of our “death-denying culture” and as an unhealthy “avoidance of physical and emotional pain” (Foster & Davidson, 2003, p. 314). This assumes a monolithic United States culture which universally denies death. The treatment of death in other American cultures is not examined. The social worker's role in this model is to facilitate conversations with dying patients and their families about healthier ways to accept death.

Social work in the hospice setting

Since the creation and codification of hospice in the United States, social workers’ roles have become more defined. Quig (1989) listed three main functions of the hospice social worker: “Prepare psycho-social assessment and develop plan of care related to the needs and problems of the patient and family; provide supportive counseling including individual, family or group therapy for patient and family; [and] make referrals to informal neighborhood resources and/or social service agencies” (p. 22). These three functions seem consonant with the job descriptions found of hospice social workers in classified ads posted today.

Some of the literature shows that social workers on hospice teams find their value on the team minimized and confused due to blurring of the roles between social work, nursing and

chaplains (Reese & Sontag, 2001). Reese & Sontag (2001) cite a study conducted in 1982 by Kuly & Davis (1987) which asked directors, staff and volunteers at 34 hospice agencies whether a social worker, a nurse, both or neither were most qualified to carry out 15 tasks outlined by NASW as appropriate for social work interventions in hospice settings. In this survey, the hospice directors thought that social workers were more qualified in only three of the categories, and said that nurses and social workers were equally qualified in nine of the categories. This implies a high degree of role blurring. This study was conducted in 1982, before hospices were required by Medicare to have social workers on staff.

MacDonald (1991) suggested that “[s]ocial work appears to be a victim of its own success. Other hospice professionals and volunteers may have integrated social work values so completely into their own values that everyone, to some degree, sees the practice of certain aspects of social work as part of his or her own function.” MacDonald (1991) writes that in order to strengthen the profession's identity, hospice social workers should focus on developing specific interventions (including applying clinical social work knowledge of psychopathology) and conducting research in the field.

In 2002 the Social Work Leadership Summit on End of Life and Palliative Care was convened to discuss practice standards for hospice social work. Drawing on this work, the National Association of Social Workers developed the Standards of Social Work Practice in Palliative and End of Life Care (NASW, 2004). The standards are: ethics and values; knowledge; assessment, intervention/treatment planning; attitude/self-awareness; empowerment and advocacy; documentation; interdisciplinary teamwork; cultural competence; continuing education; and supervision, leadership and training.

Recent research finds that although social workers have been members of hospice teams for several decades, there is still work to be done around defining social work roles on hospice and palliative care teams (Bosma, et al, 2010; Sheldon, 2000). Although the NASW Standards of Practice in Palliative and End of Life Care (NASW, 2004) lists cultural competence as a standard of practice, cultural competence is not listed as a stand-alone standard of practice or competency in the following examples.

Core competencies in end-of-life social work

Bosma, et al (2010) used a Delphi technique to solicit and synthesize opinions on the subject of the core competencies of end-of-life social work from Canadian experts in the field. The research task group identified 11 core competencies based on practice standards from the United States and the United Kingdom, and from their own practice knowledge (Bosma, et al, 2010). That list was: advocacy, assessment, care delivery, care planning, community capacity building, evaluation, decision-making, education, research, information-sharing, interdisciplinary team, and self-reflective practice.

The experts agreed that these competencies were essential for palliative and hospice social work practice. In addition, the experts suggested adding other competencies. One was “cultural competence.” 50 % of the experts agreed this should be added, while 38% thought it was already included in the eleven original competencies, and 6% felt it should not be added (Bosma, et al, 2010).

Sheldon (2000) used grounded theory and interviews with experienced social work clinicians to develop a list of essential elements of the palliative social worker. Six themes were identified: a family focus, influencing the environment, being a team member, managing anxiety, values and valuing, and knowing and working within limits.

By “family focus,” the social worker stated that she influenced families to mobilize resources to care for the ill family member and to prepare for life and death transitions. The “influencing the environment” theme dealt with case management skills, organizing finances, connecting with outside resources, and giving advice and practical information. “Managing anxiety” entailed managing anxiety of patients, family members, other staff members and the social worker's own stress, along with managing risk. “Being a team member” consisted of coordinating with other staff members to ensure the best management of the patients' “total pain,” managing the tension between patient confidentiality and information-sharing on the team, and resolving disputes between colleagues. “Values and valuing” entailed having a nonjudgmental, respectful, and empathic attitude toward patients. “Knowing and working with limits” was described as making an assessment and tailoring an intervention to the short time frame, and setting limits with and creating safety to have important discussions with patients.

None of the core role dimensions in Sheldon's study was named “cross-cultural competence.” However, several of the other dimensions included aspects of cross-cultural practice. Under the heading “being a team member” was the task “modeling for the staff” ways of respectfully interacting with patients. A social worker gave an example of a man who spoke with a thick Jamaican accent and who could not be understood by the staff.

Staff talked to him on a superficial level...So I had to have quite a frank conversation with him about this. I was prepared to stick with it because I wanted to hear everything he wanted to talk about but he would have to bear with me and I would have to ask him to repeat things and that I might actually have to ask him to write things down and that worked very well. . . . the team took this approach as well” (Sheldon, 2000, p. 495).

In addition, an aspect of “values and valuing” was “challenging discrimination” and fostering “self-determination.”

Cost of services: Staffing and case load factors

Another concern expressed by social workers in the field and doing research is that social workers are hired with less frequency by hospice agencies, and given larger caseloads. This impacts the role that these social workers can play on the teams and with their patients. Reese & Raymer (2004) found the role of social workers had declined since the advent of the Medicare hospice benefit in 1983. The authors cite the financial pressures of managed care being chief among the reasons that hospice has strayed from its initial holistic, biopsychosocial approach to dying.

In an effort to minimize cost, hospice teams have hired fewer social workers and given them caseloads that are much larger than those of nurses. Social workers are seen not as integral parts to a hospice team but as providing only an “ancillary service” in which they only visit clients in an emergency (Reese & Raymer, 2004). Although Quig lists “assessment” as one of the chief functions of a hospice social worker, Reese and Raymer (2004) found that social workers part of the intake team at only 38% of hospices, and thus did not always have the opportunity to give their clinical input on the care plan created by the team.

However, several studies have been conducted to show that social workers can actually reduce cost and increase positive patient outcomes on hospice teams (Cherin, 1997; Mahar, Eickman, & Bushfield, 1997; Paquette, 1997). Each of these studies implemented programs to increase social work involvement on hospice teams. These new programs were significantly correlated with decreased pain medication use and cost (Cherin, 1997; Mahar, Eickman & Bushfield, 1997), fewer hospitalizations (Mahar et al, 1997, Paquette, 1997), fewer on-call, after-

hours visits (Mahar et al, 1997; Paquette, 1997), and increased job satisfaction among physicians and nurses.

Reese and Raymer (2004) partnered with NHPKO to survey existing practices at 66 home hospices working with adults across the country. This survey found that the hospice agencies employed three times as many nurses as social workers, that nurses visited patients a mean of 10 times compared with only two social work visits, that social workers were involved in intakes in only 38% of the hospices, and that social workers were paid less than nurses with similar education. The authors found that social work involvement was significantly correlated with decreased hospice costs, improved patient satisfaction, increased team satisfaction, fewer visits by other members of the team, and lower severity of patient illnesses. Reese and Raymer (2004) advocate that more qualified social workers be paid higher salaries and work exclusively on social-work-oriented patient care on hospice teams to maximize these positive outcomes.

Culture and End of Life Care

One of the researcher's working assumptions is that all people live in, and are part of, numerous cultures. All social workers are from cultures, as are their patients; all social workers work cross-culturally. To best understand how cultural factors influence end-of-life issues, the literature on "culture" and "cross-cultural competence" was examined. This search turned up articles dealing with general cross-cultural clinical practice that did not discuss hospice specifically; articles about social work hospice practice which hardly ever mentioned culture; and a rich literature on cross-cultural encounters in medicine, as studied by the fields of sociology, anthropology, nursing, and medicine. In addition, there have been many articles written on cultural barriers that prevent critically ill patients from accessing hospice. However, these articles do not explore the kind of cultural concerns that patients who do enter hospice

experience with their social workers and agencies. In addition, the cross-cultural practice and cross-cultural competency of hospice social workers has not been thoroughly examined.

Culture and cultural competence

The definitions of “culture” and “cultural competence” can be difficult to pin down. This section will examine the history of the construct of “cultural competence” and how various writers have conceptualized it.

By any definition of culture, social workers have been doing cross-cultural work ever since Jane Addams and Ellen Gates Starr, two white, Protestant American woman, opened Hull House in 1889 with the goal of helping Chicago’s immigrants better adjust to life in the United States through cultural and social opportunities (Davis, 1973). Though the field has grown and changed in many ways in the ensuing century, cross-cultural work has remained a constant.

Since the 1960s, psychotherapy, based on theories originated by clinicians from Western Europe and the United States, has been challenged as to the appropriateness and effectiveness of its work with people of color, immigrants and ethnic minorities (Sue, et al, 1982). The question has been raised as to how social workers, the majority of whom are white and of the dominant culture (NASW, 2003), can best learn about and honor the cultures of each of the patients they work with, and can integrate knowledge of culture into interventions and theories to best understand and help clients.

Culture can be described as the normal, dominant and accepted practices of a group of people, but which does not predict the behavior of all people in the group (Matsumoto, 2000). The definition of culture can be very broad: “Culture is a solution to the problem of how to survive, given the problems in the environment, the physical and social needs that must be addressed, and the tools available” (Matsumoto, 2007, p. 1291).

In the cultural-competence literature, the cultures spoken of are often groups based around aspects of identity such as race, ethnicity, gender, class, and sexual orientation (Sue, Arredondo & McDavis, 1992). Derald Wing Sue, a pioneer in the field of cultural competence, defined and refined his ideas about cultural competence through a series of books and journal articles beginning in 1970s to the present. Sue wrote most frequently about people who are racial and ethnic minorities in the United States (Sue, 1977; Sue, 1978; Sue, Arredondo & McDavis, 1992).

In 1982, Sue, Bernier, Durran, Feinberg, Pedersen, Smith and Vasquez-Nuttall outlined the reasons that culturally-competent mental health care was necessary. Stanley Sue's earlier research in Washington State found that 50% of racial and ethnic minorities terminate treatment after only one session, compared to 30% of white clients (Sue, S., 1977). Sue et al noted that clinical and empirical mental health literature often portrayed only the negative aspects of people of color. This literature often attributed the problems of people of color and immigrants to genetic deficiency or cultural deficiency. Sue et al (1982) challenged both of these hypotheses as fundamentally unscientific and racist.

Later, Sue, Arredondo, and McDavis described how the field of psychology could be seen as a “handmaiden for the status quo” and promote the dominant culture’s values, even with clients who do not share those values (1992). Sue, Arredondo & McDavis (1992) issued a call the field of psychology to systematically consider the toxic effect of political and interpersonal racism, violence, genocide, forced migration, intolerance and discrimination, both historically and presently, on the lives, cultures and mental health of the minorities seen by psychologists.

Competency based practice

In order for mental health practitioners of various professions to better serve their clients, Sue et al operationalized the concept of “cross-cultural competence.” Sue et al wrote (1982) that “[c]ross-cultural counseling/therapy may be defined as any counseling relationship in which two or more of the participants differ with respect to cultural background, values and lifestyle” and, by this broad definition, “every counseling/therapy relationship is slightly cross-cultural” (p. 47). Therefore, cross-cultural counseling is not a “specialty” but is a universal component of therapeutic competency.

Sue et al proposed that cross-cultural competence in mental health was composed of three realms: awareness, knowledge, and skills. They defined the first category as the therapist's awareness of his or her own culture and biases, comfort with difference between clients and therapist, and sensitivity “to circumstances...that might dictate referral of the minority client to a member of his/her own race/culture” (1982, p. 49). The authors defined knowledge as the understanding of the United States sociopolitical system, knowledge about the specific cultural groups clients belong to, and information about the institutional barriers preventing clients from accessing services (Sue, et al, p. 49). The authors defined skills as the ability to generate a wide range of verbal and nonverbal responses in a culturally appropriate manner and the ability to “exercise institutional intervention skills on behalf of his/her client when appropriate” (Sue, et al., p. 49).

Narayan (2001) outlined six steps home health care nurses and therapists (who, like hospice nurses and therapists, deliver medical care to patients in their homes) could take toward cultural competence. The six steps are: cultivate attitudes associated with excellent transcultural care; develop an awareness of the impact culture has on the beliefs, values and practices of the

patient and the clinician (similar to Sue et al's (1982) "awareness" component); obtain background information about patients' cultures (similar to Sue et al's (1982) "knowledge" component); perform a cultural assessment; plan culturally sensitive care using a preserve-accommodate-restructure framework; and avoid defensiveness and recover from cultural mistakes. Narayan integrates the theory of cultural competence with practice knowledge of skills needed to care for patients in the home-healthcare setting. For example, Narayan suggests that clinicians, who visit patients in their homes, find out "What are 'good guest' behaviors? Is it important to be punctual? Is one expected to accept or refuse offers for food or drink? Is one expected to take shoes off when entering the house?" (p. 381). In addition, Narayan describes questions that can help clinicians make culturally-informed nutrition, medication, pain and psychosocial assessments (p. 383).

Research on Cultural Competence

Ridley, Baker and Hill (2001) point to the plurality of meanings associated with "cultural competence" and the lack of a single operationalized definition of this term as reason behind the psychology profession's "struggles to advance the conversation regarding cultural competence beyond its current position" (p. 823). The authors critique the current state of research and practice involving cross-cultural competence. They call for prescriptive, as well as descriptive, writing about cross-culturally competent psychotherapy. "It is not sufficient to define cultural competence. The desired outcomes and steps needed to achieve this purpose must be set forth" (Ridley, Baker & Hill, 2001, p. 825). The authors ask how cultural competence can be measured without an operationalized definition.

Sue's models and ideas were widely accepted, leading to revisions in the Codes of Ethics of many helping professions, including social work (NASW, 2008) and the creation of curriculum around diversity in the fields of social work, mental health counseling, psychology, psychiatry and other disciplines. In addition, many scales were developed by researchers to measure the cultural competence of students and clinicians.

The Cross-Cultural Counseling Inventory-Revised (LaFramboise, Coleman & Hernandez, 1991) is a 20-item instrument in which an evaluator observes and rates a counselor working with a client of a different racial or ethnic background. Most other measures created have been self-reports in which counselors evaluate their own skills.

Krentzman and Townsend (2008) analyzed 19 measures of self-reported clinician cultural competence for validity, reliability, relevance to social justice, definition of diversity, coherence, item clarity, and appropriateness to social work. The authors found four "promising scales for social work education" (Krentzman & Townsend, 2008, p. 17): the Multicultural Counseling Inventory (Sodowsky, et al, 1994), the Multicultural Knowledge and Awareness Scale (Ponterotto, 1996), the Miville-Guzman Universality-Diversity Scale (Miville, et al, 1999) and the Ethnic-Competence-Skill Model in Psychological Interventions with Minority Ethnic Children (Ho, 1992).

A search for more recently developed tests brought Sheu's Multicultural Counseling and Self-Efficacy Scale – Racial Diversity form (2005). This scale is the first to measure the "skills" dimension first proposed by Sue using clinician report. The MCSES–RD measures three subscales: Multicultural Intervention, Multicultural Assessment, and Multicultural Session Management. Sheu draws on previous research to argue that the efficacy of a counselor's verbal and non-verbal communication when working with a client from another culture is the true test

of cross-cultural competence, so assessments focusing on the skills of a clinician may be more revealing than the many scales which measure knowledge and awareness.

The MCSES–RD asks the participating clinician to answer all questions in the context of working with someone of a different race. Although Sheu agrees that inclusive cross-cultural counseling should pay attention to other variables such as age, ability, sexual orientation, gender identity, etc., in order for a scale to be effective, it should only attempt to measure one of these dimensions. In addition, Sheu cites Bandura (1997) in arguing that self-efficacy is a domain-dependent variable.

Thus, one may possess differing degrees of self-efficacy for working with different client groups, such as lesbian, gay, bisexual, and transgendered (LGBT) clients, racial minorities, or people with disabilities. To respond to the lack of a self-efficacy measure in the multicultural counseling literature, the current study is designed to develop and provide initial validation for a new instrument that focuses on counselors' perceived ability to effectively work with racially different clients (Sheu, 2005, p. 5).

A difference between Sheu's scale and other scales operationalizing cross-cultural competence is in the conception of “difference” and “cross” culture. Scales such as the Multicultural Counseling Inventory (MCI: Sadowsky, et al, 1994) and the Multicultural Counseling Knowledge and Awareness Scale (MCKAS: Ponterotto, et al, 2002) are written to assess a clinician's knowledge and beliefs about working with minority clients. An example of a question from the MCKAS is: “I check up on my minority/cultural counseling skills by monitoring my functioning – through consultation, supervision and continuing education.” This question seems to reflect Sue's emphasis on social justice and on adapting psychotherapy to suit

the needs of racial and ethnic minority clients. A critique of this model is that it seems geared toward white clinicians who are unfamiliar with the cultures of their immigrant, non-white or ethnic minority clients.

The experiences of clinicians of color are not as thoroughly addressed. An item in the Skills sub-scale of the Multicultural Counseling Inventory (Sodowsky, et al, 1994) poses this statement, “When working with minority clients, I monitor and correct my defensiveness.” This assumes that “minority” clients make the respondent feel defensive.

Sheu's scale does not conflate “minority client” with “someone of a different race than me.” Instead, the scale asks participants to answer the questions based on working with a client of a different race than themselves. This could mean a variety of situations: a clinician of color working with a client of color of a different race, a clinician of color working with a white client, or a white clinician working with a client of color.

Factors influencing scores on these tests

Demographic factors

Most cultural-competence scales have used self-report. Numerous demographic and educational factors appear to influence scores on these tests. For example, in initial testing and validation of the MCSES-RD, male respondents scored higher than female respondents (Sheu & Lent, 2007).

Training and experience

Increased training, whether through classes in college, graduate school or continuing education, appear to increase scores. Initial testing of the MCSES-RD found that clinicians with a Masters degree scored higher than those with a Bachelors degree, and clinicians with doctoral degrees scored higher than those with Masters degrees (Sheu & Lent, 2007). In addition,

multicultural training, in the form of classes, workshops, and supervision, correlated positively with scores on the MCSES-RD (Sheu & Lent, 2007). Holcomb-McCoy & Day-Vines (2004) found that the increase of classes and curriculum on multicultural diversity for school counselors resulted in improvements on knowledge and awareness areas of competency. Constantine and Yeh (2001) found that the number of previous multicultural courses predicted female school counselor's self-reported cross-cultural competence. In addition, Teasley, Baffour and Tyson found that total years of experience, as well as licensure correlated positively with scores on cross-cultural counseling measures for urban school social workers (2005).

Skills vs. knowledge

Several studies indicate that respondents tended to rate themselves higher at multicultural skills than at multicultural awareness or knowledge (Pope-Davis & Ottavi, 1994, Pope-Davis, Reynolds, Dings & Nielson, 1995, Sadowsky, Kuo-Jackson, Richardson & Carey, 1998).

Scores on self-report measures do not necessarily correlate with actual counseling skills. Worthington et al (2000) showed a limited relationship between scores on the self-report MCI and scores on the observer report CCCI-R. In addition, Constantine and Ladany (2000) found that scores on various cross-cultural competence self-report scales to be unrelated to written case-conceptualization skills.

Packer-Williams, Jay and Evans (2010), writing about school counselors, state compellingly that:

little is known about the degree to which multicultural diversity training aids school counselors in effectively translating what they learned into daily practice once they enter the workforce. There is also a paucity of research on the specific types of multicultural diversity practices school counselors use regularly as well

as the types of challenges typically experienced and/or anticipated in attempting to integrate the practices in their daily work (p. 5).

Clinician race

Race of clinicians also impacted scores. Latino/a, African-American and Asian-American clinicians scored higher than white clinicians on knowledge and awareness scales (Granello & Wheaton, 1998; Pope-Davis & Ottati, 1994). Initial testing of the MCSES-RD found that ethnic minority clinicians scored higher than white clinicians (Sheu & Lent, 2007).

Literature on Hospice and Cultural Competence

Only a few authors have directly studied the cultural competence or cross-cultural practice of hospice organizations and the experiences of hospice social workers doing this work. Dona Reese, a social worker who has written extensively on hospice, conducted empirical studies into institutional policies and attitudes preventing hospices from becoming more culturally competent (Reese, Melton & Ciaravino, 2004). The group also has done research on cultural reasons why African-American patients may not choose to die in hospice (Reese, Ahern, Nair, O’Faire, & Warren, 1999).

Reese, Melton & Ciaravino interviewed the directors of 22 hospice programs to learn more about kinds of culturally-competent care interventions being used and barriers to implementing culturally-competent care. Program directors expressed the most interest in providing trainings on diversity and cultural competence to staff, and evaluated their programs as doing the least well in the area of meeting the needs of “diverse” patients. Several hospice directors stated they had made no moves to provide for culturally competent care, whether due to a lack of non-white diversity among their clients, or due to the difficulty of doing the outreach

and education necessary for this goal. Other barriers identified were the scarcity of bilingual or bicultural clinicians, difficulty overcoming the prejudices or lack of knowledge about cultural difference of staff members. The program directors felt that certain characteristics of patients, such as lack of trust in the medical profession, lack of knowledge about hospice and lack of financial resources also acted as barriers to providing more culturally competent care. Other directors stated they had no difficulties implementing culturally-competent care practices and that they were adequately meeting the needs of patients not from the dominant culture (Reese, Melton & Ciaravino, 2004).

Few studies have explored the social worker's point of view on the cultural competence practices of hospice agencies. One study that elicited written narratives from hospice social workers about their "most perplexing or confusing experience" found that 31 of 32 respondents answered this question with the theme of feeling "inadequate to meet the needs of patients whose ethnic, religious or spiritual traditions were unfamiliar to them" (Wesley, Tunney & Duncan, 2004, p. 43). This suggests that hospice social workers have an interest in learning more about culturally competent interventions and find the topic of culture important. This article called for more social work education or hospice training to be focused on the ways culture impacts the dying process and ways social workers can adapt their interventions to the different, culturally-informed needs of their dying patients.

Common Themes in Cross-Cultural Hospice Work

After identifying this gap of social work literature directly examining cross-cultural encounters in hospice, the following list of common cross-cultural issues that a hospice social

worker might deal with was compiled using a variety of sources. Each item will be discussed in more depth in subsequent subsections.

1. Establishing trust across cultural differences can be made more difficult by the brief time-frame of hospice
2. Social workers may not understand culturally-bound expectations of family roles for their patients
3. Many people who identify with cultures not originating in the United States have views on disclosure that conflict with Western medical ethical and legal obligations about disclosure.
4. The medical model is oriented toward obtaining an individual's consent, but many families prefer more communal decision-making styles.
5. Language barriers and lack of interpreters on staff mean that a social worker's chief tools – words – are useless
6. Social workers unfamiliar with their client's religion, language or neighborhood may experience difficulty trying to find religious, funerary or social support resources for these clients.
7. Social workers may be asked to join in prayer or other religious ceremonies with their clients despite not sharing their religion.
8. Modern families are complicated. There is frequently more than one cultural issue at play.
9. Family members and the hospice agency may disagree on the role of the agency and the family in caring for dying loved ones.
10. Patients' lack of Western medical literacy and social workers' lack of knowledge about traditional healing practices can make communication about health issues more difficult.
11. About 90% of hospice social workers are white, meaning that on many teams, none of the social workers will share the culture of some of the patients.
12. Patients may exhibit culturally-specific maladies, which social workers may be unfamiliar with diagnosing and treating.

Establishing trust across cultural differences

Establishing trust across cultural differences can be made more difficult by the brief time-frame of hospice. As managed care has increasingly regulated hospice in the past several years, a number of social workers have found their caseloads maximized and their time with patients minimized, with social workers rarely participating in the patient's initial evaluation (Reese & Raymer, 2004). As it is, hospice stays are typically short, with half of patients dying or being discharged after 21 days and 35.4% of patients dying or being discharged after only one week (NHPCO, 2010a). This brief time-frame may be seen as a cultural issue.

Illness is often a time of raised defenses and reactivity for patient, family and social worker alike. Case material speaks to old prejudices and fears being activated at the time of death (Wise, 1999). Illness and grief can cause people to question their own culture or the culture around them (Walter, 2010). Many people of color feel distrust toward white people, including white clinicians, due to a continuing legacy of oppression of minorities in this country (Horsman, Rodriguez & Mirini, 2009). One theme that emerged from a survey of 22 hospice directors was that directors found mistrust on behalf of racial minority patients was an obstacle to providing culturally competent care (Reese, Melton & Ciaravino, 2004). Lavera Crawley, writing palliative care in the African-American community, argues that a patient's mistrust of medical institutions stems not only from historical injustices, but also from perceived racist biases from his or her current care providers, and that agencies need to examine their own current policies and practices in order to address sources of mistrust (2002).

In addition, many clinicians are just not familiar with the myriad of cultures, languages, ethnic groups and identities of their clients (Horsman, Rodriguez & Mirini, 2009, Sue & Sue, 1990) and to work with someone from a culture one has little knowledge of may require extra

research and thought. A social worker, especially one from the dominant culture, may wish for a longer time to develop rapport and respect with a patient and family, but may be limited by the brevity of the patient's stay.

Culturally-bound expectations

Social workers may not understand culturally-bound expectations of family roles for their patients. Family work is considered an important part of palliative care (World Health Organization, 2003) and hospice social work (Sheldon, 2000). In any hospice setting, understanding dynamics between family members, friends and the hospice staff is essential (Waldrop, Milch, & Skretny, 2005). Family meetings with providers toward the end of a patient's life can be contentious (Kogan, Blanchette, Masaki, 2000). The ability to navigate raucous family meetings can be in any hospice social worker's toolkit. However, culturally-bound expectations about the family roles of elders, children, women, men, and siblings influence family dynamics. Can the social worker be aware of these culturally-bound role expectations and meet a family on their own terms?

Conflict with Western medical ethics

Many people who identify with cultures not originating in the United States have views on disclosure that conflict with Western medical ethical and legal obligations about disclosure. One of the richest topics in the literature on culture and dying is that of disclosure – how much patients want to know about their medical conditions, and how much medical professionals are legally and ethically bound to tell them. The Patient Self-Determination Act, as part of the Omnibus Budget Reconciliation Act (1990) required health care institutions to notify patients in writing of their legal decision-making rights, to keep records pertaining to patients' advance directives, and to educate staff members about advance directives policies. However, the ideal of

full disclosure of a patient's illness and the insistence that a patient must make all the final decisions about his/her care runs contrary to the wishes of many groups. Many groups may prefer little or no disclosure around illness, preferring instead that the doctors tell family members, who will then be responsible for decision-making, or lie to patients in order to keep their hopes alive. Such groups include Chinese Americans (Tong & Spicer, 1991), the Navajo (Carrese & Rhodes, 1995) and Bosnian immigrants (Searight & Gafford, 2005), among many others. However, it also appears that these attitudes are neither stable nor unanimous among group members: a study by Berkman & Ko (2010) found that older Korean-American adults expressed that disclosure was negative in that it could hasten death, but positive in that it allowed people to plan effectively, and that age of the patient was important in deciding whether the doctor should give bad news or not. Conflicts may arise when family members or interpreters believe it would be bad for the patient to hear bad news, and the clinician feels it necessary to explain to the patient her or his prognosis.

Medical model

The medical model is oriented toward obtaining an individual's consent, but many families prefer more communal decision-making styles. As much research has pointed out, many people with roots in cultures outside of the Anglo-dominated cultures of the US, UK and Australia prefer a communal decision-making style to an individual decision-making style (Johnstone & Kanitsaki, 2009). Johnstone & Kanitsaki (2009) argue that medical professionals are embedded in a Western medical paradigm which privileges autonomy over collective decision-making. Social workers, as professionals working in the medical field, can face dilemmas when trying to navigate end-of-life family work while respecting the decision-making style of the family with the decision-making style mandated by the hospice agency. In Wesley,

Tunney & Duncan's survey of NHPCO social workers (2004), many respondents said their most "perplexing or challenging experience" had to do with family decision making: "respondents described situations where patients and families may have been in conflict with the social worker or each other over end-of-life choices, including denial of the need to make a choice" (p. 44).

Language barriers

Language barriers and lack of interpreters on staff mean that a social worker's chief tools – words – are useless. Family work and family-decision-making can be complicated processes, and language differences can make these conversations twice as long and rife with misunderstandings. When communicating in a second or seventh language, people can become frustrated looking for the right word and trying to communicate, and this increase of distress can affect the ability to describe events accurately (Westermeyer & Janca, 1997). When ill or dying, many people who learned English later in life may decide to communicate only in their mother tongue. This may frustrate monolingual hospice workers and family members alike. Although it is highly recommended to use trained interpreters, (Leanza, Boivin, & Rosenberg, 2010) with the lack of trained medical interpreters who speak the patient's language, or a failure on the part of agencies to hire such interpreters, social workers may be tempted to use family members as interpreters. Using a family member has its own risks, such as the family member imposing his/her own agenda on the conversation (Leanza, Boivin, & Rosenberg, 2010). Many questions can be raised about working across a language barrier or with an interpreter: How can a social worker navigate his/her role if a personal care attendant or physician speaks the patient's language but the social worker does not? How can a social worker lobby for increased agency investment in interpreters?

Resources and social support

Social workers unfamiliar with their client's religion, language or neighborhood may experience difficulty trying to find religious, funerary or social support resources for these clients. Resource-finding is one of the key roles of hospice social workers (Quig, 1989). In hospice, some of the important resources social workers find for clients are religious. Wesley, Tunney and Duncan (2004) found that 91% of the NHPCO hospice social workers they surveyed linked their patients with clergy. Social workers unfamiliar with the religious practices of their clients may find it difficult to make referrals to places of worship, burial grounds, alternative healers, crematoriums and other services. Social workers who do not speak their client's language or are not familiar with their client's neighborhood may have difficulty finding and communicating with the proprietors of these services.

Participating in cultural rituals

Social workers may be asked to join in prayer or other religious ceremonies with their clients despite not sharing their religion. A survey by Wesley, Tunney and Duncan (2004) found that 60% of respondents reported praying with their patients and 25% reported leading their clients in prayer. Religion is often tied to culture. Understanding enough about the meaning of rituals a client wishes to participate in seems an important task.

Modern families are complicated

There is frequently more than one cultural issue at play. Cross-cultural partnerships, adoptions, and chosen families can make all issues mentioned above even more complicated, as practice knowledge attests. Families are not necessarily mono-cultural groups. What if a woman in hospice has Pentacostal parents who only speak Spanish, Catholic and Vodou-practicing in-laws who speak Haitian Creole and English, and a child who speaks English? What if they all

have different ideas on the meaning of health, recovery, death, heaven and hell? A social worker connecting with this family would have to be skilled at cross-cultural practice and at holding and honoring the differences among each of the family members.

Who is in charge?

Family members and the hospice agency may disagree on the role of the agency and the family in caring for dying loved ones. Families might feel protective of their loved one and not wish to have non-medical (psychological, caretaking, etc) intervention from an agency (Yeo & Hikoyeda, 2000). Families that value children caring for dying parents may have trouble accepting the help of strangers from the hospice agency. On the other hand, a family may inaccurately be perceived as not services by a hospice agency or hospital because of active family involvement (Wallace & Lew-Ting, 1992).

Medical literacy and traditional healing practices

The patients' lack of Western medical literacy and social workers' lack of knowledge about traditional healing practices can make communication about health issues more difficult. People might not know what a DNR entails or how a ventilator will impact their family member (Pierson, 2000). Social workers may not understand how the herbs a healer prescribes can interact with a patient's other medicines. In addition, understanding both client expectations about hospice and medical care is important. African-American patients might want their doctors to use aggressive care to extend their lives, and might experience a hospice referral as their physicians giving them substandard care and letting them die (Mouton, 2000). However, research shows that hospice can actually *prolong* life, especially with certain medical conditions. For example, a study followed 4,493 patients with congestive heart failure or cancer of the breast, colon, lung, pancreas, or prostate who either entered hospice or did not. The researchers

found that hospice entry *increased* survival in four of the six diagnostic categories, with survival increased from 321 days to 402 days for congestive heart failure patients, and with shorter increases in lung, pancreatic and colon cancer (Connor, Pyenson, Fitch, Spence, Iwasaki, 2007). This information seems pertinent for hospice care providers to know and to disseminate throughout the communities they work in, so that families can make the most informed decisions about their healthcare choices.

Lack of shared culture

About 90% of hospice social workers are white, meaning that on many teams, none of the social workers will share the culture of some of the patients. In Csikai's (2004) nationwide survey, 91% of the social workers identified as white, and 61% identified as Christian. In the year 2000, white Americans comprised about 75.1% of the population (U.S. Census Bureau, 2000), which means that white social workers are probably overrepresented in the hospice field. This trend is seen in the social work field in general. According to an NASW study, 95% of social workers in Massachusetts are white, 3% are Hispanic and 1% are black (NASW Center for Workforce Studies, n.d.).

On the other hand, Christians make up closer to 79% of the population (U.S. Census Bureau, 2000), and thus appear under-represented in Csikai's study. One issue that may arise out of this demographic make-up is that none of the hospice social workers share the cultures of the clients being served. Recent research on medical residents showed that although all the participants denied any racial bias, all the non-black residents displayed pro-white and anti-black bias on implicit bias tests that affected the type of care they would give (Green, Carney, Pallin, & Long, 2009). If the results could be applied to social workers, this would mean that although the

profession disavows racism and tries to overcome it, unconscious bias may still be affecting social workers' care decisions.

Disease classifications are culture-bound

Researchers have argued that the symptoms of mental illness, as well as the disease classifications of mental illness (such as the various iterations of the Diagnostic and Statistical Manual), are culture-bound, and reflect “historical development, cultural influence and political negotiation” (Kleinman, 1988). Certain mental illnesses are culture-bound, meaning they appear primarily in certain cultures.

As an example, anorexia nervosa has been proposed as a culture-bound syndrome in Westernized countries (Swartz, 1985) and examples of other culturally-bound symptoms include hikikomori in Japanese culture (Teo & Gaw, 2010), brain fag in Nigerian student culture (Prince, 1985), kyol goeu in Khmer culture (Hinton, Um, & Ba, 2001), nervios and ataque de nervios in Puerto Rican culture (Guarnaccia, Lewis-Fernández, & Marano, 2003) and shenjing shuairuo in Chinese culture (Lee & Kleinman, 2007; Lee, 1999). Social workers trained in the United States may have limited knowledge of these syndromes and may struggle to diagnose, understand and assist hospice patients experiencing or naming their symptoms this way.

Western Bioethics, Autonomy, and Hospice

The values of hospice care are embedded in a larger international discourse on the changing nature of end-of-life care in industrialized societies. Western principles of bioethics guide how physicians and other healthcare workers, including social workers, treat their patients. Johnstone & Kanitsaki (2009) have written convincingly on how strict adherence to bioethics can be problematic when working with families from more collective cultures. These authors

synthesize much current research about shifts in end-of-life care from an American and Australian perspective. Johnstone & Kanitsaki find that a belief in individual autonomy is at the core of Western biomedical ethics, and state that “in Australian, Canadian, United States and United Kingdom health care contexts, autonomy is seen as empowering” (2009, pp. 409) and for this reason, models of care emphasizing autonomy are developed for end-of-life care. This means that individuals are encouraged to actively plan for what kind of treatments they would like when they are dying, and to make these decisions without the “coercion” of others.

Johnstone & Kanitsaki (2009) cite research on various ethnic populations (East Asian, Bosnian immigrant, Japanese, Korean Americans, Mexican Americans, African Americans, Middle Eastern Lebanese, Greek Australians), which consistently demonstrated that “group consensus and decision making by family are more valued than individual decision making” in these cultures (p. 409). This would indicate that hospice models which emphasize individual choice, informed consent and autonomy under all possible conditions may be culturally inappropriate for many groups.

Foster & Davidson (2003) describe the tend to dichotomize the locus of control as being either within a patient or within a doctor, and have documented how more control has been given to the dying patient over the past several decades in American medicine. However, there are other methods of examining which parties have control during the dying process.

Sue (1978) challenged psychology’s bias toward an internal locus of control, and stating this bias was Western in origin and was used to pathologize patients who maintained different, culturally-bound worldviews. Schroepfer, (et al, 2009) a social worker, examines the literature pertaining to forms of control in the dying process. Writing that “the dying process is often seen as the ultimate loss of control,” Schroepfer then examines the “stress that can result from a lack

of control during the dying process” (p. 58) and methods of promoting a sense of control in patients. One of the key concepts comes from the research of Rothbaum, Weisz & Snyder (1992) on “primary control,” “secondary control” and “vicarious control.” Rothbaum, et al define primary control as “bringing one’s environment into line with one’s wishes” (p. 5). An example might be a patient deciding on a specific treatment course. This type of control seems most clearly associated with the ideal of autonomy.

Secondary control is defined as “bringing themselves into line with environmental forces” (Rothbaum, et al., p. 5). Rothbaum and colleagues do not see behaviors such as passivity, withdrawal and submissiveness as indicators that control has been surrendered, but that a different type of control – secondary control – is probably being used. A specific type of secondary control is vicarious control, defined as “obtaining a sense of control through powerful others who one believes are able, and likely, to exert control on one’s behalf in the situation” (Schroepfer, 2009, p. 64). These “powerful others” may be physicians, family members, God or other agents. In any scenario, the patient wants these outside agents to use their power to make choices on their behalf, and trusts that these choices are best.

Schroepfer cites research which found that women with perceptions of either primary or vicarious control had a better adjustment to breast cancer (Taylor, Helgeson, Reed & Skokan, 1991). Schroepfer calls these different orientations “control preferences” and makes the case that control preferences are flexible, depending on personality, situation, time and context. For example, an elder may have one sort of control preference at home and another one while hospitalized, and one sort of preference with physicians and one sort with family and friends. Schroepfer et al write that sensitivity to the dying individual’s control preferences on behalf of caretakers and members of the social support group is essential: “Expressing and exercising

one's control preference may only be possible for dying elders if they receive the support necessary to exercise their control preference successfully" (2009, p. 67). A failure to attune to a patient's control preference can lead to patient dissatisfaction.

Research by Worthington, et al (2000) indicates that clinicians who are open to an external locus of control in assessing a client's difficulties are rated by observers to have higher levels of multicultural competence.

It should be noted that we are not suggesting that counselors must make external or sociocultural attributions for the causes of clients' problems in order to be multiculturally competent, but that one aspect of MCC is openness to nondispositional aspects of problem formation (p. 466).

How different cultures navigate death

The researcher next examined studies on how ethnic groups in the United States who are under-represented in hospice engage with the dying process. Across all cultures, there is a paucity of research about how members of cultural groups and their families engage in hospice. There are usually more studies about why certain groups are under-enrolled in hospice, or how these cultures perceive death, or the medical field, or advance directives. These related studies have been included to give a very brief general overview of some of the issues that might be pertinent to these cultural groups.

Native Americans

In 2004, the Census Bureau estimated the Native American and Alaska Natives population to be about .09% of the US population (Humes, et al, 2011). However, only 0.2% of hospice patients in 2009 were Alaska Native or American Indian (NHPCO, 2010a). A study of

114 medical records of deceased patients from one Indian Health Service Area by Kitzes and Berger (2004) found that although 59% of the charts documented physician conversation with the patient about the prognosis, none of the charts documented a conversation with the patient or family about home care or hospice care, and that there had been no palliative care guidelines in place at the hospitals studied. On the positive side, all of the hospitals studied had room for rituals, and an “open-door policy” for traditional healers. Many American Indians and Alaskan Natives believe that surrounding an ill or dying person with relatives will ease their suffering (Lewis, 1990). One frequently-cited study by Carresse & Rhodes (1995) explored how Navajo patients preferred to talk about death and illness. The authors interviewed 34 Navajo adults about provider communication and advanced directives planning. Most of the interviewees stated that it was important to think, speak and act in a positive manner at all times, even regarding illness, and 86% of respondents stated that advance directive planning was a dangerous violation of Navajo values. This was a clear indicator that a Western biomedical model that favors informed consent and full disclosure around illness would be culturally dystonic among the Navajo. However, there is considerable heterogeneity between tribes, and the attitudes of the Navajo are not representative of those of other tribes.

African-Americans

Elioff (2003) studied the reasons why African-Americans, who make up 12.6 % of the US population (Humes et al, 2011), constitute only 8% of the hospice population. She cited ways in which the values of many black patients diverge from their dominant-culture caregivers. Black patients and doctors may favor more aggressive treatments, even at the very end of life, to express a value that life is precious at any cost. This contrasts with the medical community's increasing reliance on advance directives which implicitly encourage the individual's right to

refuse care through Do Not Resuscitate, do not intubate and other orders aimed at not prolonging life after a certain point (Johnstone & Kanitsaki, 2009). Group decision-making may be valued in black patients' families, which contrasts with the medical community's value of "autonomy." Cort (2004), a sociology professor, wrote about the phenomenon of "cultural mistrust" that many members of the African-American community have of the medical community, and how that factors in to fewer African-Americans wanting to die in hospice settings. Mistrust of the medical system, based on a long legacy of medical abuse and discrimination against black people in this country, may be prominent (Cort, 2004), and African-American patients may be especially opposed to palliative care programs that favor stopping treatment and just "letting the patient die" as this may seem like medical neglect. Many black patients do not want to enter hospice due to fears that there will be no black staff members or religious clergy, or because they do not want strangers in their homes (Elioff, 2003). Cort (2004) states that this fear of not seeing one's ethnicity reflected in the staff of the hospice team is real, and writes that most hospices cannot attract adequate numbers hospice volunteers or staff members of color. Elioff, herself a black hospice clinical social worker, gives three case examples of African-American patients who died in hospice care, including both of her parents. She and the patients found the experiences positive. Elioff (2003) describes the ways she and other members of the team worked to address the concerns of one patient's family.

Elioff and Cort espouse similar recommendations for increasing the number of African-American patients who use hospice services, and for improving the experience of these patients at the end of their lives. Hospice could be made more culturally relevant and accessible if hospice did more outreach to black civil and religious leaders to educate them on the goals of hospice and the services that hospice provides, such as 24-hour care, which many people don't

know about (Elioff, 2003, Cort 2004). Elioff (2003) and Cort (2004) also recommend that hospice team members try to understand the fears and mistrust of African-American patients who come to them. Elioff's (2003) research indicated that more needs to be done to understand how to promote cross-cultural empathy on hospice teams, and to study the efficacy of outreach efforts. Cort (2004) cited two palliative care agencies, the Harlem Palliative Care Network and the Hospice of the Valley, in Santa Clara, CA, who had succeeded in improving their care and increasing ethnic or racial minority enrollment. In each case, assuring that members of the target community were involved in decision-making, whether as board members, staff, volunteers or outreach workers surveying community members, was vital (Cort, 2004). Cort also recommended hiring competent African-American staff members, encouraging all staff members to respect clients' cultural preferences, involving friends and family members in decision-making, and conducting public-service campaigns through the media to educate community members about hospice.

Hispanic/Latino

NHPCO reports that in 2009, 5.3% of hospice patients identified as Hispanic or Latino. The US Census estimates that in 2010 Hispanics made up about 16% of the total population (Humes, et al, 2011), meaning that Hispanic patients are under-enrolled in hospice. This seems partially due to the young age of Hispanic people as a group: the mean age for Hispanics in 2005 was 27 for men and 27.6 for women, compared to 35.2 for men and 37.8 for women in the United States as a whole (US Census bureau, 2000). However, the youth of the Hispanic population probably does not account for all of the discrepancy.

A qualitative study of 20 Hispanic hospice users and non-users living in a rural area found these barriers to accessing hospice: lack of health literacy, worries about invasion of

privacy, lack of health insurance, language barriers (Carrion, 2010). The participants identified a need for more Spanish-speaking staff and Spanish-language educational materials about hospice.

The ten patients who were in hospice stated they had overcome these barriers because of a need for extra assistance, a prior knowledge of hospice, and the place of referral – in this study, patients referred to hospice during a hospital admission were more likely to choose hospice than patients referred by their primary care doctor. Hispanic elders are more likely to live in the community and less likely to use long-term care (Talamantes, Lawler, & Espino, 1995). Both US-born and foreign-born Mexican-American elders express a preference to live with their children if they become ill (Angel, Angel, McClellan & Markides, 1997). Other researchers have suggested physicians may refer fewer Hispanic patients to hospice because they observe the patient living at home and being cared for by their families, and may believe hospice would be unnecessary or culturally inappropriate (Wallace & Lew-Ting, 1992).

Asian and Pacific Islander

An estimated 5.1% of Americans identified as being of Asian or Pacific Islander (API) descent in 2010 (Humes, et al, 2011), however, only 1.9% of hospice enrollees were Asian or Pacific Islander in 2009 (NHPCO, 2010a). The literature suggests that many API families value communal decision-making and even if a dying patient is capable of making decisions, his or her children may feel duty-bound to make the decisions as a symbol of love and respect (Yeo & Hikoyeda, 2000).

A recent study by Fernandes, et al (2010) found that a palliative care agency geared toward low-income immigrants from Asian and Pacific Islands in Hawaii had positive results, including decreased hospitalizations among patients, increased discussion and documentation of end-of-life wishes, and high caregiver satisfaction. About 98% of the patients in the study were

racial minorities: Samoans, Filipinos, Japanese, Micronesians, and Hawaiians. The agency employed a large number of providers, including outreach workers, who spoke the languages of their patients, along with interpreters. This research demonstrated that culturally sensitive in-home palliative care can improve patient outcomes and quality of life.

Summary

The literature demonstrates that culturally competent care is needed in all sectors of psychotherapy and the helping professions. Hospice is a relatively new form of medical care. Social workers are a part of almost every hospice team, and they visit patients in their homes, work with patients' families and friends, and perform case management and counseling. Nearly 40% of all deaths in America occur in hospice, and that number increases every year (NHPCO, 2010a). Despite hospice's growing reach, racial, ethnic and linguistic minorities are underserved by hospice. Institutional and cultural barriers exist which prevent people of color from accessing hospice at the same rates as whites. There is a paucity of research into the cultural competence of hospice social workers. Little is known regarding how competent these clinicians feel doing cross-cultural work with their patients, or what types of interventions they use. There is no scale which specifically measures the cross-cultural competence of hospice social workers which takes into account their unique duties of working with clients at the end of their lives, in a time-limited fashion. This research aims to address this gap by adapting a validated scale for use with hospice social workers to measure their perceived competence at working with clients of a different race than themselves.

CHAPTER III

Methodology

Overview

The aim of this descriptive exploratory study was to learn more about how social workers employed in licensed hospice settings in New England evaluate their competencies as cross-cultural practitioners. Do experienced social worker's score differently than inexperienced social workers on self-ratings of cultural competency? Is longer tenure as a hospice social worker associated with higher self-ratings of cultural competency? Do hospice social workers who speak multiple languages report higher cultural competency scores than mono-lingual hospice social workers? How would hospice social workers in New England rate their perceived abilities to perform various clinical tasks with a client of a different race than themselves? How would variables such as the survey participants' race, gender, age, years of experience as a social worker and as a hospice social worker, and education impact self-rating scores?

Research design

A quasi-experimental, quantitative survey research design was used. A purposive sample was used recruit the sample of professional hospice social workers. Survey responses were compared between groups formed by variables such as race, gender, age, years of experience and education. A quantitative design was used in order to compare a group of social workers on the same metric: their responses on the Multicultural Counseling Self-Efficacy Scale–Racial Diversity, Revised Version, for Use in Hospice Settings (MCSES-RD(R)) (Begans, 2011).

Sample

Inclusion criteria. To participate in the study, the participants needed to 1) have earned a Master's degree in social work 2) be employed 10 hours or more a week in a licensed hospice setting in one New England state, 3) be English speakers, and 4) have agreed to participate voluntarily in the study as evidenced by signing an Informed Consent document.

Exclusion criteria. Participants were excluded from the study if they 1) did not have a Master's degree in social work, 2) were employed fewer than 10 hours a week in a licensed hospice setting in New England, 3) did not speak English or 4) did not return a signed Informed Consent document with their survey materials.

Recruitment strategies. The goal was to recruit as many hospice-employed social workers in one New England state as possible, in the hopes of attaining a sample close to representative of the demographics of hospice social workers in this region. I did not actively recruit clinicians of color or members of other oppressed populations.

Sample size. A total of 35 survey packets were returned to the researcher. Two were excluded: one packet did not include a signed Informed Consent document, and one participant wrote the researcher a note stating that his/her clients were almost all white, and that he/she did not have enough experience doing cross-racial hospice work to answer questions about the subject. Therefore, the final N=33.

Sample Characteristics. The modal participant in this sample was a White, mono-lingual, female in her 40's or 50's who had been a social worker for an average of 18 years and in hospice practice for an average of 8 years. The sample consisted of 33 respondents, the majority of whom were women (n=27; 81.8%). Almost one third of those sampled (n=12; 36%) spoke another language besides English, including French (n= 6), Spanish (n= 5), Hebrew (n=1),

Haitian (n=1), American Sign Language (n=1), and Italian (n= 1). Only one participant identified as multiethnic, and wrote in two Western European heritages. There were no clinicians of color in this sample. The mean age for participants was 54 years; 3% (n=1) were in their twenties, none were in their thirties, 27.27% (n= 9) were in their forties, 36.36% (n=12) were in their fifties, 30.30% (n= 10) were in their sixties, and 3% (n=1) were in their seventies.

Social workers in the survey all held a master's degree in social work and had been in practice for an average of 18.33 years (range 1-48 years; $SD=11.74$) and had worked an average of 8.12 years ($SD=7.94$) in a hospice setting at the time of the survey. Most worked full time ($x=33.5$ hours per week).

Recruitment Procedures

Identifying agencies

Finding and contacting potential participants took several months. The National Hospice and Palliative Care Organization maintain a comprehensive list of hospices, by state. By going to <http://www.nhpc.org> and clicking on the "Find a Provide" link, a search engine was generated. By putting the name of the state in the location field, a list of all the hospices and palliative care facilities registered with NHPCO in the Commonwealth of Massachusetts was produced. There were 77 facilities listed, along with the main phone number and office headquarters of each agency.

Next, each hospice was called and an attempt made to speak with a social worker on the staff (see Appendix A for the script used during phone calls). By speaking with potential participants over the phone, the researcher hoped to describe the study and recruit at least one social worker at that agency willing to receive the research packet.

Using this approach, 77 agencies were called. This resulted in phone conversations with 29 social workers or agency directors at 29 agencies. Of these 29 social workers, 28 agreed to receive the study packet. Each social worker who was reached was also asked how the researcher could contact other colleagues in a similar position who met inclusion criteria at their agency. Fifteen volunteered to distribute survey packets to their colleagues. Using this “snowball” technique, a total of 59 survey packets were mailed. Of the agencies, 3 reported only providing palliative, not hospice, care, 4 had merged with other hospices on the list, 1 did not exist anymore, and 1 location had no social worker.

In preparation for the large number of telephone calls to be completed, a Google Voice account was set up so that the study had a local phone number and unlimited free calling. The phone script, and voice mail scripts, can be found in Appendix A. These were strictly followed for each phone call.

Ethics and Safeguards

Risks of participation

As with any research involving human subjects, this study carried risks for participants. The risks of this particular study were considered minimal. However, the questions on the survey did ask participants to evaluate their own cross-cultural practices. This self-reflection on the potentially charged subject of racial attitudes and the self-evaluation of clinical practice might have caused some participants to feel negatively about themselves. In addition, participants might have felt frustrated at the length of the survey and the process of mailing it back to the researcher. Since the research subjects were all licensed social workers, the

researcher did not distribute a resource packet to help direct them to mental health professionals in the area. All identifying details will be held in confidence.

Benefits of participation

This research examined a relatively unexplored piece of hospice social work practice: that of the cross-cultural competence of its practitioners. Social workers who feel comfortable with their cross-cultural practice might have felt rewarded by the attention given to this subject and might have felt good when reflecting on their own practice. Other participants might have felt inspired to start a dialog about cross-cultural competence with their colleagues after taking this survey. Hopefully, the social workers who participated understand that their responses will help to expand the knowledge of researchers from many different fields.

Voluntary nature of participation

Participation in the study was completely voluntary. Participants who spoke with the researcher over the phone were asked if they wished to receive survey material in the mail. Other participants were given copies of survey materials by their colleagues. Filling out the survey and returning it was voluntary. Due to the anonymous nature of the survey, participants could not ask that their data be removed after submitting it to the researcher.

Informed consent procedures. A copy of the Informed Consent document can be found in Appendix B. Participants received two copies of the document in their survey packets – one to sign and send back to the researcher and one to keep for their records. Participants in the survey were English-speaking adults able to understand and sign their own consent forms.

Precautions taken to safeguard confidentiality and identifiable information

In the initial phone contact with a social worker for an agency, the researcher learned the name of at least one social worker from each potential survey site, and addressed the survey

envelopes to these social workers. Each returned envelope was assigned a unique identification number before it was opened, and the Informed Consent and data forms were be marked with that unique identifier. The Informed Consent documents were separated immediately from the data forms and kept in a separate, locked file. Only the researcher has access to the signed consents.

No personally identifying information such as name and agency worked for is asked in the questionnaires. The researcher provided self-addressed, stamped envelopes, one per each survey sent. The return address was the researcher's address, so that participants did not need to indicate which hospice they work for. Some social workers put identifying information on an envelope (such as ones who decided to use a larger envelope than the one provided) and those envelopes were dissociated from the data. The names of the social workers contacted will never be included in the data.

Human subjects review board (HSRB)

The HSRB at Smith College School for Social Work in Northampton, Massachusetts approved this study after assuring that all materials met federal and college standards for protection of human subjects. (A copy of the HSRB's approval letter is in Appendix C.)

Data Collection

Overview

Demographic data were collected to compare participants on important variables, such as age, sex, race, languages spoken, education, years of experience as a social worker, years of experience in hospice, and hours worked per week.

Quantitative data were collected in the form of the Multicultural Counseling Self-Efficacy Scale – Racial Diversity, Revised Version for hospice use survey, a 37-item Likert questionnaire (Sheu, 2005, Begans, 2011). The original instrument was developed by Hung-Bin Sheu, PhD (2005). The researcher wrote to Dr. Sheu and received his permission to modify and use the scale with hospice social workers (H. Sheu, personal communication, January 20, 2011).

The instrument has three subscales: Multicultural Intervention, Multicultural Assessment, and Multicultural Session Management. The scale instructs participants as follows: “When working with a client who is *racially different* from you, how confident are you that you could do the following tasks effectively over the next week?” Participants are asked to score their response on a 0-9 scale, with 0 being “No Confidence at All” and 9 representing “Complete Confidence.”

Screening process

All participants who submitted the questionnaire with a signed informed consent were included in the study if they met inclusion criteria. Of the 35 packets received, 33 met inclusion criteria.

Informed consent procedures

Two copies of the Informed Consent document were included in the packet sent to each social worker who agreed by phone to participate in the study. Participants were asked to read the informed consent and, if they agreed to participate, sign the informed consent and include the informed consent along with the completed questionnaire. The second copy was for the participant to keep. Survey packets returned without a signed Informed Consent were not included in the study. A copy of the informed consent can be found in Appendix B.

Survey Instruments

Overview

The survey packet was 10 pages long. The following was contained in the packet: 1) letter of introduction and instruction on how to fill out the survey (Appendix F), 2) two copies of the Informed Consent (Appendix B), 3) Demographic Questionnaire (Appendix D), 4) the Multicultural Counseling Self-Efficacy Scale – Racial Diversity, Revised Version for Use in Hospice Settings, and 5) a self-addressed, stamped envelope for the return of the survey material.

Instrument selection

The literature on testing cultural competency in various settings was reviewed in order to identify a self-rating tool suitable for administration in hospice settings to social workers. The Multicultural Self-Efficacy Scale–Racial Diversity (MCSES-RD) scale (Sheu, 2005) was identified as a potential rating scale, but in order for it to be used in this project, the language in several items needed to be modified for the question to be relevant to the hospice/social work setting.

The MCSES-RD is a 37-item Likert scale. It is the first (and only) scale developed exclusively to measure the self-perceived skills domain identified in Sue's model of cultural competence. Designed originally to test the cultural competencies of counseling psychologists, the scale “allows us to take a close look at what counselors believe they can do, as opposed to what they know, when working with racially diverse clients” (Sheu, 2005, p. 61).

The scale asks participants, “When working with a client who is *racially different* from you, how confident are you that you could do the following tasks effectively over the next week?” The tasks are routine therapeutic behaviors such as “When appropriate, adopt different

helping roles other than counselor/therapist (e.g., mentor, consultant, advocate, coach)” and “Repair cross-cultural impasses that arise due to problems in the use or timing of particular skills (e.g., introduce the topic of race into therapy when the client is not ready to discuss).”

The items on the scale were developed through extensive brainstorming, testing and revising by Sheu. The tasks operationalized in the questionnaire were generated based on the literature on counseling stages/processes and multicultural counseling, and the questions were revised based on feedback from experts (doctoral-level psychologists) and through testing on an undergraduate population (Sheu, 2005). The scale measures three factors: Multicultural Intervention, Multicultural Assessment, and Multicultural Session Management.

A strength of the MCSES-RD is that it only measures cross-racial counseling skills, as opposed to trying to measure the much broader category of cross-cultural counseling skills.

The term “cross-cultural competence” can be used to describe clinicians’ skills working with either oppressed populations or across differences of race, ethnicity, class, affectional orientation, religion, sex, age, et cetera (Sue, Arredondo & McDavis, 1992). Sheu limits the scope of the MCSES-RD to racial difference. This is helpful for many reasons. Sheu cites Bandura in stating that “self-efficacy is a domain-specific concept” (Bandura, 1997, cited in Sheu, 2009, p. 5). Sheu continues:

Thus, one may possess differing degrees of self-efficacy for working with different client groups, such as lesbian, gay, bisexual, and transgendered (LGBT) clients, racial minorities, or people with disabilities. ...[T]he current study is designed to develop and provide initial validation for a new instrument that focuses on counselors’ perceived ability to effectively work with *racially different* clients (2005, p. 5, emphasis added).

In their articles on cross-cultural competence, Sue, Arredondo and McDavis use the term “minorities” to describe African-Americans, American Indians, Asian-Americans, and Hispanic and Latinos, the “four major minority groups in our society” (1992, p. 478). However, Sue et al also wrote that “all counseling is cross-cultural” and wrote about “special populations, such as women and gays and lesbians” (1992, p. 478). Scales such as the Multicultural Knowledge and Awareness Scale (Ponterotto, 2002) ask participants about their practice working with “minorities.” The use of the term “minorities” in cross-cultural competence scales is problematic for two reasons. The word “minorities” could refer to many kinds of minorities: racial minorities, ethnic minorities, sexual minorities, etc. Without a definition, respondents could be answering questions about work with different populations. In addition, questions about working with minorities on a cross-cultural competence scale implies that the clinician respondent is not a minority, which is obviously not always true.

Dr. Sheu granted permission modify the scale items for use with hospice social workers (personal communication, January 20, 2011). The 37-item questionnaire was reviewed and 15 items were identified for revision (see Table 1). Some questions in the original tool did not apply to tasks that hospice social worker routinely perform. For example, items referring to termination were not relevant to hospice social work. In hospice, the termination process usually involves death and is involuntary, so the wording had to be changed. The targeted questions were modified while trying to keep them within the spirit of the original question, and measuring the same factors (either Multicultural Intervention, Assessment, or Session Management).

Table 1

MCSES-RD(R): Original and Modified Statements

Original MCSES-RD items	Modified items
Help the client to articulate what she or he has learned from counseling during the termination process	Help the client to articulate what she or he has learned from the hospice experience
Where appropriate, help the client to explore racism or discrimination in relation to his or her presenting issues.	Where appropriate, help the client to explore racism or discrimination in relation to coping with end-of-life issues.
Keep sessions on track and focused with a client who is not familiar with the counseling process.	Keep sessions on track and focused with a client who is not familiar with hospice or the counseling process.
Respond effectively to the client's feelings related to termination (e.g., sadness, feeling of loss, pride, relief).	Respond effectively to the client's feelings related to dying.
Encourage the client to take an active role in counseling.	Encourage the client to take an active role in their end-of-life decisions.
Identify and integrate the client's culturally specific way of saying good-bye in the termination process.	Identify and integrate the client's culturally specific way of saying good-bye to their loved ones.
Assess the client's readiness for termination.	Assess the client's readiness to discuss death and dying issues.
Interpret standardized tests (e.g., MMPI-2, Strong Interest Inventory) in ways sensitive to cultural differences.	Help clients complete advance directives forms in ways sensitive to cultural differences.
Deal with power-related disparities (i.e., counselor power versus client powerlessness) with a client who has experienced racism or discrimination.	Deal with power-related disparities (i.e., social worker power versus client powerlessness) with a client who has experienced racism or discrimination.
Use non-standardized methods or procedures (e.g., card sort, guided fantasy) to assess the client's concerns in a culturally sensitive way	Use non-standardized methods or procedures to assess the client's concerns in a culturally sensitive way.
Help the client to develop culturally appropriate ways to deal with systems (e.g., school, community) that affect him or her.	Help the client to develop culturally appropriate ways to deal with systems (e.g., hospitals, the legal system) that affect him or her.
Assess culture-bound syndromes (DSM-IV) for racially diverse clients (e.g., brain fag, neurasthenia, nervios, ghost sickness).	Assess culture-bound beliefs around death and dying for racially-diverse clients.
Help the client to set counseling goals that take into account expectations from her or his family.	Help the client to set end-of-life goals that take into account expectations from her or his family.
Admit and accept responsibility when you, as the counselor, have initiated the cross-cultural impasse.	Admit and accept responsibility when you, as the social worker, have initiated the cross-cultural impasse.
Treat culture-bound syndromes (DSM-IV) for racially diverse clients (e.g., brain fag, neurasthenia, nervios, ghost sickness).	Facilitate culture-bound rituals around dying for racially diverse clients.

CHAPTER IV

Findings

Scale Construction

The revised Multicultural Counseling Scale–Racial Diversity (MCSES-RE(R): Begans, 2011), designed for the purpose of surveying hospice social workers, was completed by 33 master’s level social workers who were practicing at least 10 hours a week in a hospice setting in Massachusetts. Cross-cultural competence in mental health is composed of three realms: awareness, knowledge, and skills (Sue, et al, 1982). The MCSES-RD(R) measures clinicians’ self-perception of their competence at multicultural counseling skills. Scale items probed for self-assessment of the hospice worker’s perceived ability to manage or respond professionally in specific cross-cultural practice scenarios.

Cronbach's alpha was used to examine the internal consistency of the revised scale. Internal consistency results indicate that the scale is highly reliable (37 items; $\alpha = .973$), suggesting that items were tapping similar constructs. Subscale alphas were similarly robust.

Table 2

Internal consistency of the Revised Multicultural Counseling Self-Efficacy Scale–Racial Diversity

Multicultural Counseling Self-Efficacy Scale – Racial Diversity, Revised	Total # items	# revised items	α
All items, totaled	37	15	.973
Subscales			
Multicultural Intervention subscale	24	5	.966
Multicultural Assessment subscale	6	4	.804
Multicultural Counseling Session Management subscale	7	6	.898

Hypotheses testing:

Based on a careful review of the sparse hospice-related cross cultural literature, it was anticipated that hospice social workers would score somewhat low on the revised MCSES-RD. Previous studies report that hospice social workers found cross-cultural interactions with clients to be especially “perplexing or confusing” (Wesley, Tunney, & Duncan, 2004). However, the null hypothesis, predicting low scores, was rejected. The mean MCSES-RD(R) score for all participants was 7.55 ($SD = .82$) on a scale where 0 = “no confidence” and 9 = “total confidence.”

In addition, moderate and significant correlation was found between years of experience as a social worker and score on the MCSES-RD(R). Pearson's r was used to measure the correlation between the interval-level demographic variables and scores on the MCSES-RD(R) and each of the subscales.

Table 3

MCSES-RD(R) Scores by Years of Experience in Hospice Settings (N=33)

	n	Pearson r	Significance (2-tailed)
MCSES-RD(R)	30	.390	.033*
Multicultural Intervention	30	.382	.037*
Multicultural Assessment	33	.361	.039*
Multicultural Session Management	33	.309	.080

Note: * = $p > .05$

There was a moderate positive correlation between years as a social worker and score on the total scale ($r=.390$, two-tailed, $p=.033$). There was a moderate positive correlation between years as a social worker and scores on the Intervention subscale ($r=.382$, two-tailed, $p=.037$, two

tailed) and Assessment subscale ($r=.361$, two-tailed, $p=.039$), but no significant correlation on the Session Management subscale. No positive correlation was found between other sample characteristics such as the race or years of education of the respondent, number of languages spoken, or gender on ratings of cultural competency using the revised MCSES-RD.

A t-test was computed to compare more experienced social workers with less experienced social workers. A median split was used to divide the respondents with 18 or fewer years of experience from those with 19 or more years of experience. A significant difference was found ($t(28)=3.085$, two-tailed, $p=.005$). Those with less experience had a lower mean scale score ($X=7.14$) than those with more experience ($X=8.0$).

T-tests were computed to examine the difference between more and less experienced social workers on all the three subscales. On the Intervention subscale, a significant difference was found ($t(28)=2.906$, two-tailed, $p=.007$, two-tailed). Those with less experience had a lower mean scale score ($X = 7.11$) than those with more experience ($X = 7.97$).

A t-test was run to determine if there was a difference in the mean of the Assessment subscale by those with 18 or fewer years experience compared to 19 or more years of experience. A significant difference was found ($t(31)=2.596$, $p=.014$, two-tailed). Those with less experience had a lower mean scale score ($X=6.78$) than those with more experience (7.58).

A t-test was run to determine if there was a difference in the mean of the counseling management subscale by those with 18 or fewer years experience compared to 19 or more years experience. A significant difference was found ($t(31)=2.795$, two-tailed, $p=.009$, two-tailed). Those with less experience had a lower mean scale score ($X = 7.71$) than those with more experience ($X = 8.38$).

Table 4

MCSES-RD(R) Scores by Years of Experience (N=33)

Scale or Subscale	Years of experience	N	Mean	SD	Standard Error
MCSES-RD(R) Total Score	0-9 years	7	6.83	.27	.11
	10-19 years	9	7.39	.96	.32
	20-29 years	9	8.15	.72	.24
	30+ years	5	7.72	.73	.33
	Total	30	7.54	.86	.16
Multicultural Intervention Subscale	0-9 years	7	6.71	.24	.09
	10-19 years	9	7.42	.97	.32
	20-29 years	9	8.14	.76	.25
	30+ years	5	7.67	.89	.40
	Total	30	7.51	.91	.17
Multicultural Assessment Subscale	0-9 years	7	6.52	.50	.19
	10-19 years	10	6.96	1.13	.36
	20-29 years	11	7.69	.87	.26
	30+ years	5	7.35	.82	.37
	Total	33	7.17	.96	.17
Multicultural Counseling Session Management	0-9 years	7	7.47	.50	.19
	10-19 years	10	7.88	.94	.30
	20-29 years	11	8.47	.56	.17
	30+ years	5	8.20	.58	.26
	Total	33	8.04	.76	.13

A one-way ANOVA was computed to examine differences in scores on the revised MCSES-RD based on years of experience as a social worker. Respondents were divided into four groups: those who had been in practice 0-9 years, 10-19 years, 20-19 years, and more than 30 years. Significant differences were found between groups ($F(3,30) = 4.47, p = .012$). As one can see in Table 5, the mean score for the 0-9 years group was 6.83, the mean score for the 10-19 year group was 7.39, the mean for the 20-29 years was 8.15, and the mean for the 30 or more

years group was 7.72. A Bonferroni post hoc test showed the significant difference was between those with 0-9 years of experience and those with 20-29 years experience.

For the Intervention subscale there was a significant difference between the 4 groups ($f(3,26)=4.567, p=.011$). A Bonferroni post hoc test showed the significant difference was between those with 0-9 years of experience and those with 20-29 years experience.

For the Counseling Management subscale: there was a significant difference between the 4 groups ($f(3,29)=3.250, p=.036$). A Bonferroni post hoc test showed the significant difference was between those with 0-9 years of experience and those with 20-29 years experience.

Table 5

One-way ANOVA: Impact of Years of Experience on MCSES-RE(R) Scores (N=33)

		df	F	Significance
MCSES-RD(R) Total	Between Groups	3	4.47	.012*
	Within Groups	26		
	Total	29		
Multicultural Intervention subscale	Between Groups	3	4.56	.011*
	Within Groups	26		
	Total	29		
Multicultural Assessment subscale	Between Groups	3	2.69	.065
	Within Groups	29		
	Total	32		
Multicultural Counseling Session Management subscale	Between Groups	3	3.25	.036*
	Within Groups	29		
	Total	32		

Note: * = $p > .05$

There was no significant difference between the four groups in the Assessment subscale.

T-tests were run to determine if there were differences in the four scales by the hours worked per week. The respondents were divided into part-time groups (those working 20-32

hours per week) and full-time group (those working 33-40 hours per week). A significant difference was found in the Assessment subscale ($t(31)=2.338, p=.028$, two-tailed). The part time group had a lower mean (6.79) than the full time group (7.53). No significant differences were found in the other scales.

Anecdotal Findings

Two respondents added written responses on the survey materials. One participant wrote that he or she had scored high on this measure because for many years: “I worked with a racially diverse, poor, population in [a large city]. I have been a social worker in [this New England state] for the past [several years] working almost exclusively with a white population, an experience that would otherwise leave me little prepared for working with a racially diverse family regardless of how much 'book knowledge' I had on the subject.”

Another respondent wrote that the questions on the MCSES-RD(R) were geared toward individual therapy, while much of hospice social work is with families. “In hospice practice the patient and family are the unit of care, NOT the patient alone. People who are in pain, nauseous, constipated, etc. do not usually engage in a therapeutic process like what happens with people who are physically in relatively good health....Due to ever increasing progress in the diagnosis and treatment of end stage illness people are coming to hospice care later and later in their life. There are very few people with enough strength and awareness to engage in any kind of 'therapy.'...Most of social work is done with families.”

The next chapter will discuss the findings and implications for future work in this research area.

CHAPTER V

Discussion

This chapter discusses study findings in the context of the current literature on cultural competence and hospice social work. The strengths and limitations of this study are reviewed, and suggestions for further research and implications for social work education and practice are described.

Current Findings and Previous Literature

Using the version of the Multicultural Counseling Self-Efficacy Scale – Racial Diversity, (Sheu, 2005) modified for hospice use, a major finding is that hospice social workers in this small sample rated their cross-racial counseling skills highly, with a mean total score of 7.55 (SD=.82) on a scale of 0-9, where 9 signifies “Complete Confidence” and 0 indicates “No Confidence at All.”

Total MCSES-RE(R) scores

The original hypothesis anticipated that hospice social workers would display a lack of confidence in their self reports of cross-cultural hospice practice skills, was disproved by the findings. This hypothesis originated from a “hunch” gained during the researcher’s first year clinical training internship in a medical social work environment with numerous terminally ill patients. Patients often struggled with end-of-life questions and sometimes made choices which confounded the medical team and the hospice teams. Some of these decisions seemed firmly based in culture, and stimulate the researcher’s interest in learning more about the apparent

disconnect between medical culture and the beliefs and assumptions patients bring from their own culture to the death and dying experience.

An assumption that informed this hypothesis is that there is a paucity of literature on cross-cultural hospice social work practice and a corresponding lack of opportunities for education and training about culturally-informed models of intervention and assessment, theory about what the components of culturally competent hospice care would look like, or suggestions for future education.

In one of the only studies touching on the cross-cultural practice of social workers, Wesley, Tunney & Duncan (2004) found that 31 out of 32 respondents reported their most “confusing or perplexing” experience involved feeling “inadequate to meet the needs of patients whose ethnic, religious or spiritual traditions were unfamiliar to them” (p. 43). Char Elioff (2003) has written one of the few articles from the perspective of a clinician of color working with clients of color. Eliof (2003) describes her clinical experiences with African-American hospice patients and families, and her own parents’ experiences of hospice and dying. Elioff advocated increasing outreach to African-American communities, and described ways that hospice agencies and practitioners could adapt their practice to be culturally attuned.

The literature notes that scores on the Skills subscales of self-report measures tend to be higher than the Knowledge and Awareness subscales (Pope-Davis & Ottavi, 1994; Pope-Davis, Reynolds, Dings & Nieldson, 1995; Sadowsky, Kuo-Jackson, Richardson & Carey, 1998). The question of why the skills scores tend to be higher than knowledge or awareness scores is not resolved in the literature. However, it seems that the high scores of social workers on the MCSES-RD(R) might be related to the scale measuring the Skills construct. In addition, it is important to note that research has indicated scores on self-score scales do not necessarily

correlate with scores on observer-report scales (Cartwright, Daniels & Zhang, 2008; Worthington, 2000).

The next section examines the scores on each of the three subscales and discusses these in light of findings the cross-cultural competency literature.

Subscale: Multicultural counseling interventions

The first subscale, Multicultural Counseling Intervention, included 24 items. The mean score for this sub-scale was 7.51 ($SD = .87$). Five questions in this sub-scale were adapted for hospice social work settings (for example, the word “counselor” was changed to “social worker” and questions about termination were rewritten to be about death and dying).

The lowest scoring item in this scale was “Help the client identify how cultural factors (e.g. racism, acculturation, racial identity) may relate to his or her maladaptive relational patterns” ($X=6.23$; $SD=1.89$). MacDonald (1991) has suggested hospice social workers are suspicious of attempts to find pathology in the normal processes of dying, and one wonders if the some social workers do not see their clients as having “maladaptive relational problems” and thus scored low on this item.

Another low-scored item on the same subscale, with a mean score of 6.57 ($SD=1.906$), used a similar phrase: “maladaptive beliefs and conflicted feelings.” If this hospice-adapted scale were to be the focus of future research, it would be useful to ask hospice social workers their qualitative responses to questions implying clients' pathology and social workers' ability or responsibility to change this pathology.

The highest-scoring item in this scale, with a mean of 8.24 ($SD=.867$), was “Help the client to utilize family/community resources to reach her or his goals.” This item emphasizes the hospice social worker's competence connecting with family members and larger systems in the

community, consistent with the literature on hospice social workers' roles (Bosma et al 2010; NASW, 2004; Sheldon, 2000).

Subscale: Multicultural assessment

The second subscale, Multicultural Assessment, contained six items. Four of the items were modified from the original. The mean score was 7.17 ($SD = .96$). The lowest scoring item in this subscale was “Select culturally appropriate assessment tools according to the client's cultural background” ($X=6.06$; $SD=1.903$). One study found that only 38 % of social workers reported participating in assessments of new clients (Reese & Raymer, 2004). Some of the social workers in this research sample may not be involved in hospice assessments of new patients and may lack familiarity with assessment tools or perhaps may not see assessment as part of their roles at their agencies. If this survey tool were to be refined, additional information about the agency-specific roles of participant hospice social workers might be added.

The highest-scoring item on the Multicultural Assessment subscale, with a mean of 7.63 ($SD=1.185$), was “Assess culture-bound beliefs around death and dying for racially-diverse clients.” Hospice social workers discuss death and dying with patients and families on a daily basis. Talking about the details of a client's view on death and dying seems to be a hospice social work specialty.

Subscale: Multicultural counseling session management

The third subscale, Multicultural Counseling Session Management, contained seven items. Six were modified from the original scale. The mean score on the subscale was 8.04 ($SD = .76$). The lowest scoring item in this subscale, with a mean of 7.652, was still higher than the highest scoring item on Multicultural Assessment.

The highest scoring item in this subscale and in the entire instrument, with a mean score of 8.52 (SD=.795), was “Encourage clients to take an active role in their end-of-life decisions.” This question, modified by the researcher, is biased toward a view that a client taking an “active role” is better than being “passive.” The question implies that counselors who foster activity and autonomy in patients are more culturally competent than those who encourage or support passivity. This seems to indicate that both the researcher and the social workers are embedded in a Western medical culture whose ethics value autonomy (Johnstone & Kantisaki, 2009).

The privileging of autonomy in the medical and psychological fields has been critiqued by many researchers and theorists. Sue (1978) suggested this belief was used to “pathologize” clients who endorsed a more fatalist worldview. The use of the word “active” in this question might be problematic, as there are numerous connotations for that word, and it might be measuring different constructs. Rothbaum et al (1992) distinguish between two forms of control: primary and secondary. Primary control, which is most closely related to notions of autonomy and activity, is defined as “bringing one’s environment into line with one’s wishes” (Rothbaum, et al, 1992, p. 5). Secondary control is defined as “bringing themselves into line with environmental forces” (Rothbaum, et al, 1992, p. 5). In this model, behaviors which might be considered by medical culture to be “passive,” such as a patient trusting a family member to make medical decisions for her, are considered another form of autonomous control called “secondary control.” Thus, what one clinician sees as “passivity” may be viewed by another as “activity.” The question does not define “active role” and thus leaves it to the clinicians to define.

Clinician experience

The literature suggested several hypotheses about the effect of social worker demographic characteristics on MCSES-RD(R) scores. Clinicians with more years of experience as professional social workers and as hospice social workers were expected to score more confidently on measures of cultural competence skills (Teasley, Baffour & Tyson, 2005). A major finding was that there was a significant correlation between clinician years of experience as a social worker and scores on the MCSES-RD(R). Clinicians with more experience scored higher on all subscales and the total MCSES-RD(R). The correlation was in the moderate range scale ($r=.390$, two-tailed, $p=.033$). These findings are consistent with research showing experience to positively correlate with score on cross-cultural counseling competence.

Education, race and gender effects

Clinicians with more education, clinicians of color, and male clinicians were expected to score higher on the MCSES-RD(R). However, the effect of clinician race and education could not be measured because all clinicians reported being white or European-American and all clinicians held Masters degrees. Due to the small sample size ($N=33$) there were only six male participants and the effect of gender on scores could not be studied.

Strengths and Limitations of the Study

This study set out to answer the question: how do hospice social workers assess their cultural competency skills?

Strengths

The strengths of the study are in the findings, which provide a baseline for other research in the field of hospice social work cultural competence. The researcher modified an existing

scale, the MCSES-RD, which was originally created for counseling psychology. Some of the changes made to the scale were basic, such as changing the word “counselor” to “social worker” throughout. Other changes were more substantial, such as re-writing all questions about termination to be about death, since most social worker-client relationships end not by voluntary termination but by death in hospice social work. Further psychometric testing would be necessary to determine how effectively this modified scale measures the cross-cultural skills of hospice social workers. However, the scale showed high internal validity (Cronbach's alpha = .97), indicating that, despite the modifications, the questions seem to be asking similar things.

In adapting the MCSES-RD for hospice workers, numerous articles on the roles of hospice workers were consulted. However, these articles often made reference to a need for greater elaboration on these roles and functions (Bosma, et al, 2010, McDonald, 1991; Reese & Raymer, 2004; Sheldon, 2000). Through reading them, it was sometimes difficult to grasp what a hospice social worker does on a daily basis.

Limitations

One of the major limitations of this study was the small sample size (N=33). Accessing hospice social workers without a listserv or membership directory of a national hospice social worker organization was difficult. The method of contacting social workers via telephone proved a stumbling block, as hospice social workers spend most of their days visiting patients, not at their desks answering phone calls.

The demographics domains surveyed in this study were used both to ensure participants met eligibility requirements and also to gather information about differences between participants might affect outcomes. However, the convenience sampling procedures produced a very homogeneous sample. For example, on the race/ethnicity question, all respondents checked

“white” or other European-American heritage, so it was impossible to compare respondents based on race. In addition, all respondents had a Master's degree, so it was not possible to compare respondents based on level of education. The demographics questions could have been expanded to search for meaningful differences between respondents – such as differences in number of hours of cultural-competency education taken, or percentage of caseload composed of clients of color.

Another limitation is that the researcher is not a hospice social worker, and had only limited experience with hospice social workers through an internship as a medical social worker and through family experience with hospice, and therefore may not have had a sufficiently comprehensive understanding of the range of responsibilities of hospice social workers. This could have resulted in important dimensions of their work and skills not being included in the revised scale.

One respondent wrote a lengthy comment, suggesting that in future research, the MCSES-RD(R) could be adapted to focus more on family work, writing that most patients are in hospice for a very brief time and in too much physical discomfort to do traditional therapy. However, their families are often the ones who deal with the social worker. The respondent wrote: “Most of the social work here is done with families.” If the study were to be replicated, eliciting qualitative feedback on the questions from a panel of hospice workers would be necessary. In addition, more research could be done into cultural competence measures designed for family therapists.

Implications for Practice and Policy

The results of this study demonstrate that this sample of hospice social workers rated themselves highly on cross-racial cultural competence, and that their competence increased with years of experience as social workers. These are positive preliminary findings.

However, this research must be considered along with other research in the field. A survey of 22 hospice directors found that barriers such as lack of bilingual or bicultural clinicians, cost of diversity training and other programming, difficulty of doing outreach to minority communities, and the prejudices and ignorance of staff members were all barriers for agencies in trying to become more culturally competent (Reese, Melton & Ciaravino, 2004). The institutional climate of agencies should be considered along with the competencies of individual workers in evaluating the cultural competence of the hospice field. As hospice use continues to rise, and the United States population continues to age and diversify, preparing all hospice workers, whether nurses, physicians, chaplains, home health aides or social workers, for culturally competent practice will be essential, from both a logistic and social justice perspective. Hospice directors may use research such as this study as a jumping-off point for an agency-wide discussion about cross-cultural competence.

In addition, this research showed that more experienced clinicians rated themselves as more competent than less experienced clinicians. While nothing can replace field experience, schools of social work could consider adding more coursework about medical social work and death and dying issues to their coursework, or integrating these issues into coursework on diversity.

Recommendations for Future Research

If further progress were to be made in the study of hospice social workers' cross-cultural competence, several different avenues of research could be taken in the expansion of the MCSES-RD(R), or in the development of new scales.

In the development of new scales or the expansion of this one, the family focus of hospice social work would be important to keep in mind. As one participant recommended in a written comment, the MCSES-RD(R) could be further updated to include more items about working with patients' families, as "the patient and the family are the unit of care, NOT the patient alone." A literature review of the cultural competence measures developed for family therapists could be compiled. Perhaps one of these scales could be adapted for hospice social work.

Hospice social workers could be consulted, through in-person interviews, focus groups, or qualitative surveys, regarding their feedback to the MCSES-RD(R), and the scale could be updated to reflect what hospice social workers feel are their most important cross-cultural tasks. Qualitative studies could also be conducted to determine what kinds of interventions, assessment techniques and attitudes hospice social workers use when working cross-culturally. This would also be an important contribution to the literature on social workers' roles on the hospice team.

Racial diversity is not the only kind of diversity. Additional scales could be developed to measure different kinds of cross-cultural competence, with groups such as bisexual, lesbian, gay, or transgender patients and families, disabled patients or families, or patients or families who practice a different religion than the hospice social worker.

Future cross-cultural competence measures might make changes in the demographic questions asked in order to locate meaningful relationships between these variables and the data.

For example, the data shows that people of color are under-represented in hospice (NHPCO, 2010a). Therefore, a demographic question which asks “What percentage of your current caseload are clients of color?” would help researchers to understand the relationship between experience with clients of color and cross-racial cultural competence.

The sample in this survey was small and fairly homogenous, in terms of race and educational attainment. Future surveys might consider studying the cross-cultural competence and practices of hospice social workers of color. Such research would further work by clinicians such as Elioff (2003) who write about the perspectives and contributions of social workers of color on hospice teams.

Conclusion

Hospice teams serve over a million patients (not to mention their families) each year, and about 40 % of deaths in America take place while enrolled in hospice care programs. With social workers as members of most hospice teams, it is evident that our field plays an important role in the final act of many American lives. This research has shown it is possible to adapt existing scales measuring cross-cultural competence to the unique tasks and functions of hospice social workers. The research shows a moderate correlation between experience as a social worker and perceived cross-racial competence. It is the researcher’s hope that this will be one of many studies focusing on the cross-cultural competence of hospice social workers, with the goal of better understanding and promoting cross-cultural competence in the field.

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Appendix A

Telephone and Voicemail Contact Script

Researcher: I will telephone the main number of the agency and ask to speak with the social work supervisor. If there is no supervisor, I will ask to speak with any social worker. Once connected, I will introduce myself and follow the script below:

Telephone Script

Researcher: Hello, my name is Jessica Begans. I'm an MSW candidate at Smith College School for Social Work, and I am doing a research project about hospice social work as part of my master's degree requirements. I got the name of your agency from the National Hospice and Palliative Care Organization database.

Would you be able to speak with me for 2-3 minutes about your agency?

[If no] Thank you. Is there a better time I could call back?

[If yes] Thank you.

I have a few questions about social work services at your agency. Could you tell me how many social workers are employed at your location? Thank you. How many staff members have their MSW or higher? Thank you. How many of them work more than 10 hours a week? Thank you.

My research involves asking hospice-employed MSW social work staff to complete a brief questionnaire and mail it back to me.

Would you be willing to participate in the survey yourself?

[If yes] Thank you. What is your mailing address, so that I can send you the survey?

[If no] Thank you.

I would like to invite as many social workers as may be interested to participate. Can you suggest a way that I might contact other social workers at your hospice about participating in the survey?

[If the social worker suggests either that the researcher call the other social workers on the phone, or that the researcher send the surveys to the agency for this contact person to distribute] Great! Could I have that person's phone number?
[or] Could you tell me the mailing address?

[If the social worker suggests another means of contact, such as email or a poster] Thank you. Actually, would it be possible for me to call that person? Or, would you feel comfortable distributing the surveys among the other social workers in your office? Thank you.

[If at any point the social worker asks what the research is about] The survey is designed to help us learn more about the cross-cultural practice of hospice social workers.

Voicemail Script

Researcher: Hello, my name is Jessica Begans and I'm an MSW candidate at Smith School of Social Work. I got your agency's name from the NHPCO database. I am conducting a research study on hospice social work and would like to include social workers from your hospice in the study.

I would be very appreciative if you could call me back so I could explain a little bit about the study. The call would take about 5 minutes. My number is ***-***-****.

Thank you very much.

Appendix B

Informed Consent

Dear Participant,

Hello! My name is Jessica Begans, and I am a Master's degree candidate at Smith College School for Social Work. I am conducting research on the cross-cultural practice of social workers on hospice teams. This study involves surveying hospice social workers about their perceived abilities to perform various clinical tasks with racially different clients. The data I gather will be analyzed for my Master's thesis **and will be presented and possibly published.**

To participate in this research, you must hold a Master's degree in social work and be employed at least 10 hours a week in an adult hospice facility in [New England state]. You must be able to read English and have signed this Informed Consent document. **You have received two copies of this letter – one to sign and return to me with your survey, and the other to keep with your records.** To participate in this research you will fill out a brief questionnaire. The first part of the questionnaire asks questions about your gender, age, ethnicity, level of education and experience in the field. The second part of the questionnaire is a 37-question survey about your cross-cultural practice. The survey should take between 15-20 minutes to complete. When you are done, you are asked to return this informed consent form and the questionnaire in the self-addressed, stamped envelope and put it in the mail to me.

I do not anticipate that participants in this study will incur serious risks while completing this survey. However, while filling out the form you may feel stressed about the self-reflection necessary for this exercise. You may also experience benefits from this research, such as the opportunity to think about new strategies for delivering culturally competent hospice care. In addition, the fields of social work, palliative care and health care in general will benefit from the information you share. Monetary compensation will not be provided.

You will not be asked to reveal any personally-identifying information such as name or date of birth in the questionnaire. The return envelope uses the researcher's address as the return address. You will sign your name the Informed Consent document **so your name will be known to the researcher. However, I will keep all your personal information confidential. I will never share information about your response with your agency.** My advisor will have access to the paper surveys and data extracted from them only after any identifying details have been removed. In publications or presentations, the data will be presented as a whole and the location of this survey will be disguised. All data will be kept in a secure, locked cabinet for three years, **per federal regulations. If I need the data past this time frame, the data will be kept until they are no longer needed,** then destroyed.

Participation in this study is completely voluntary! You may withdraw from this study at any time during the data collection process. You may refuse to answer any question, and you may decide not to send in a survey you have completed. **If you would like to withdraw your response from the study after sending it in, you may do so by contacting me by April 14, 2011.** If you have any concerns about your rights or any aspect of the study, please call me at ***-***-**** or contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at 413-585-7974.

Sincerely,

Jessica Begans

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Your signature

Thank you!

Please return one copy of this form in the envelope with your survey, and keep one copy for your records.

Appendix C

Smith College School for Social Work Human Subjects Review Board Approval Letter

February 25, 2011

Jessica Begans

Dear Jessica,

Your revised materials have been reviewed and they are fine except for one small thing. In your Application you now say the research is for the presentation and publication of your thesis. You say in the flier it's for the publication of your thesis. Both of these comments are not quite right. You don't want to be limited like this. The data is for your thesis AND for possible presentation and publication. You have it right in the Consent.

We are happy to approve your submission with the understanding that you will make these corrections on your final copy which you'll send to Laurie Wyman for your permanent file.

Please note the following requirements:

Consent Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project. There are so many strong cultural attitudes and rituals around illness and death; it will be fascinating to see what you learn.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee
CC: Elizabeth Irvin, Research Advisor

Appendix D

Demographic Questionnaire

This survey is designed to learn about multicultural counseling experiences of hospice social workers. There are no right or wrong answers. Also, you and your agency will not be identified at any time.

Please complete the demographic items listed below. Following the demographic section, you will find a list of statements related to multicultural counseling. Please read instructions and each statement carefully and do not skip any of them. Thank you for your participation!

1. Sex: Female Male

2. Do you speak any languages other than English Yes No
If yes, please indicate which other language(s) you speak.

3. Please indicate your Ethnic background:
 - African American
 - Asian American/Pacific Islander
 - Latino/a American
 - Multiethnic (specify): _____
 - Native American/Alaskan Native
 - White American

4. Your age, in years: _____

5. Highest educational degree earned:
 - Master's Ph.D. Other (specify):

6. Field of study: MSW Other (please specify):

7. How many years have you been in practice as a social worker? _____

8. How many years have worked in a hospice setting? _____

9. How many hours a week are you currently employed in a hospice setting as a social worker? _____

Appendix E

Multicultural Counseling Self-Efficacy Scale–Racial Diversity© (Sheu and Lent 2004)

Revised Version for Use in Hospice Settings (Begans 2011)

Instructions: The following questionnaire consists of 37 items asking about your perceived ability to perform different social work behaviors with individual or family clients who are **racially different** from you. Using the 0-9 scale, please indicate how much confidence you have in your ability to do each of these activities **at the present time**, rather than how you might perform in the future. Please circle the number that best reflects your response to each item.

When working with a client who is *racially different* from yourself, how confident are you that you could do the following tasks effectively over the next week?

	No Confidence at all				Some Confidence			Complete Confidence	
1. Openly discuss cultural differences and similarities between the client and yourself.	0	1	2	3	4	5	6	7	9
2. Address issues of cultural mistrust in ways that can improve the working relationship	0	1	2	3	4	5	6	7	9
3. Help the client to articulate what she or he has learned from the hospice experience	0	1	2	3	4	5	6	7	9
4. Where appropriate, help the client to explore racism or discrimination in relation to coping with end-of-life issues.	0	1	2	3	4	5	6	7	9
5. Keep sessions on track and focused with a client who is not familiar with hospice or the counseling process.	0	1	2	3	4	5	6	7	9
6. Respond effectively to the client's feelings related to dying.	0	1	2	3	4	5	6	7	9
7. Encourage the client to take an active role in their end-of-life decisions.	0	1	2	3	4	5	6	7	9
8. Evaluate counseling progress in an on-going fashion	0	1	2	3	4	5	6	7	9
9. Identify and integrate the client's culturally specific way of saying good-bye to their loved ones.	0	1	2	3	4	5	6	7	9
10. Assess the client's readiness to discuss death and dying issues.	0	1	2	3	4	5	6	7	9
11. Select culturally appropriate assessment tools according to the client's cultural background	0	1	2	3	4	5	6	7	9
12. Help clients complete advance directives forms in ways sensitive to cultural differences.	0	1	2	3	4	5	6	7	9
13. Deal with power-related disparities (i.e., social worker power versus client powerlessness) with a client who has experienced racism or discrimination.	0	1	2	3	4	5	6	7	9

When working with a client who is *racially different* from yourself, how confident are you that you could do the following tasks effectively over the next week?

	No Confidence at all			Some Confidence			Complete Confidence		
14. Use non-standardized methods or procedures to assess the client's concerns in a culturally sensitive way.	0	1	2	3	4	5	6	7	9
15. Take into account the impact that family may have on the client in case conceptualization.	0	1	2	3	4	5	6	7	9
16. Assess relevant cultural factors (e.g., the client's acculturation level, racial identity, cultural values and beliefs).	0	1	2	3	4	5	6	7	9
17. Take into account cultural explanations of the client's presenting issues in case or task conceptualization.	0	1	2	3	4	5	6	7	9
18. Repair cross-cultural impasses that arise due to problems in the use or timing of particular skills (e.g., introduce the topic of race into therapy when the client is not ready to discuss).	0	1	2	3	4	5	6	7	9
19. Conduct a mental status examination in a culturally sensitive way.	0	1	2	3	4	5	6	7	9
20. Help the client to develop culturally appropriate ways to deal with systems (e.g., hospitals, the legal system) that affect him or her.	0	1	2	3	4	5	6	7	9
21. Manage your own anxiety due to cross-cultural impasses that arise.	0	1	2	3	4	5	6	7	9
22. Assess culture-bound beliefs around death and dying for racially-diverse clients.	0	1	2	3	4	5	6	7	9
23. Help the client to set end-of-life goals that take into account expectations from her or his family.	0	1	2	3	4	5	6	7	9
24. Help the client to identify how cultural factors (e.g. racism, acculturation, racial identity) may relate to his or her maladaptive relational patterns.	0	1	2	3	4	5	6	7	9
25. Manage your own racially or culturally based counter-transference toward the client (e.g., over-identification with the client because of his or her race).	0	1	2	3	4	5	6	7	9
26. Encourage the client to express his or her negative feelings resulting from cross-cultural misunderstanding or impasses.	0	1	2	3	4	5	6	7	9
27. Assess the salience and meaningfulness of culture/race in the client's life.	0	1	2	3	4	5	6	7	9
28. Take into account multicultural constructs (e.g., acculturation, racial identity) when conceptualizing the client's presenting problems.	0	1	2	3	4	5	6	7	9

When working with a client who is *racially different* from yourself, how confident are you that you could do the following tasks effectively over the next week?

	No Confidence at all				Some Confidence			Complete Confidence	
29. Help the client to clarify how cultural factors (e.g., racism, acculturation, racial identity) may relate to her or his maladaptive beliefs and conflicted feelings.	0	1	2	3	4	5	6	7	9
30. Respond in a therapeutic way when the client challenges your multicultural counseling competency.	0	1	2	3	4	5	6	7	9
31. Admit and accept responsibility when you, as the social worker, have initiated the cross-cultural impasse.	0	1	2	3	4	5	6	7	9
32. Help the client to develop new and more adaptive behaviors that are consistent with his or her cultural background.	0	1	2	3	4	5	6	7	9
33. Resolve misunderstanding with the client that stems from differences in culturally based style of communication (e.g., acquiescence versus confrontation).	0	1	2	3	4	5	6	7	9
34. Remain flexible and accepting in resolving cross-cultural strains or impasses.	0	1	2	3	4	5	6	7	9
35. Facilitate culture-bound rituals around dying for racially diverse clients.	0	1	2	3	4	5	6	7	9
36. Help the client to utilize family/community resources to reach her or his goals.	0	1	2	3	4	5	6	7	9
37. Deliver treatment to a client who prefers a different counseling style (i.e., directive versus non-directive).	0	1	2	3	4	5	6	7	9

Appendix F

Introduction Letter

Dear Hospice Social Worker,

Can you help me? I'm researching cross-cultural hospice social work, and need clinicians like you to fill out a brief, confidential survey about your cross-cultural practice. I'm an MSW candidate at Smith School for Social Work, and I will use this research for the publication of my Master's thesis.

To participate in this research, you should be a social worker with an MSW or more advanced degree in social work, and should be employed at least 10 hours a week at a hospice agency serving adult patients in Massachusetts. Participation is voluntary, and your responses will be kept completely confidential. Neither you nor your agency will be identified by participating in this research.

Your opinion on this important topic matters!

Please do not hesitate to contact me if you have any questions. Thank you so much for your time and interest in this project!

Sincerely,

Jessica Begans
Smith School for Social Work
(***)***_****