

**BETWEEN CULTURES, BETWEEN LIFE AND DEATH**

**A Qualitative Study of the Experiences of Health Care Professionals Providing  
Hospice Palliative Care for Ethno-Cultural Others**

by

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## **Abstract**

This thesis deals with the qualitative investigation of the experiences of Eurocanadian health care professionals who provide hospice palliative care for the patients, families, and friends from other ethno-cultural groups in the context of the multicultural city, Vancouver. The research consists of semi-structured interviews with open-ended questions with six care providers from various disciplines. The interview data are presented under the common themes: (1) the staff's perspectives on culture, (2) family issues, (3) verbal communication, and (4) communication and interaction without or beyond language. Then, the data are analyzed with the concepts of "communitas or antistructure", "I and Thou", "individual" and "inner healer" in relation to "structure", "I and It", "person" and "work persona". The analysis suggests that "communitas or antistructure", "I and Thou", "individual" and "inner healer" "inner healer" are the dominant themes in this analysis of hospice palliative care. Here, the non-verbal communication and interaction often force the health care professionals to experience a raw and profound connection with the patients, far exceeding the verbal. In addition, the basics, norms and common sense of Western health care are frequently reconsidered, reexamined, and questioned. In particular, this tendency is more evident in providing care for the patients from other ethno-cultural backgrounds. Yet, the appropriate balance between antistructure and structure, "I and Thou" and "I and It", and "inner healer" and "work persona" needs to be established according to each individual situation. In the conclusion, the paper suggests that the core and essence of hospice palliative care originates from the communitas or antistructural experience in cross-cultural encounter in the death and dying context, against the common belief that its origin is the Christian context.

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## 1. Introduction

### 1.1. prelude

He who binds to himself a joy  
Does the winged life destroy;  
But he who kisses the joy as it flies  
Lives in eternity's sunrise.

*Eternity* by William Blake

*"You are my only true friend ...." An old Englishman was trying to talk to me holding my hand. But he could barely speak. He was out of breath, out of energy, and out of time.*

He was dying alone at a palliative care unit in Vancouver. I am a volunteer in this unit. We had become friends several weeks earlier. From his room, he saw me walking in the hallway and said, "Hello, my best friend!!" That was the first time we met. We talked for hours. He didn't have family in Canada, neither do I. He was from England and I'm from Japan. He was in his seventies and I was in my twenties. He was Christian and I am Buddhist. We talked about everything, everyday. We were true friends.

*He used up all of his breath, energy, and time to pray for my study, my future and me, not for himself.*

*"Please God, help his study ... Please ... his future ... Please God ... bless him ...."*

I've learned more profoundly, more truthfully, and more purely about Life and myself from these kinds of experiences than from all the education I've had, both academic and religious. I have been studying the death and dying issue from socio-cultural, psychological and spiritual aspects for over ten years. I've been educated and trained as well as worked as a Buddhist priest for over twenty years. The question is why the best teaching comes from the scenes of death and dying. In particular, why do I learn the most from my experiences with dying people in Canada where I am a stranger or alien, rather than in Japan, my home country? And why have I had the best lessons from the patients from outside Canada?

Based on this view of mine, the study inquires about why and how the experience of facing death and dying issues in the cross-cultural encounter is so special.

Many people come to Canada from many countries, for many reasons. They speak many languages, believe in many religions, have many beliefs, practice many rituals and have many lifestyles. They vary in every aspect of life when they first arrive in Canada. Most of them try to maintain their lifestyles while they live in Canada. In other words, they attempt to keep their identities and personas as intact as possible.

However, when one is moving from one country to another, his/her identity(ies) and persona(s) structured in the old country are usually being destroyed. Furthermore, when s/he is transiting from life to death, s/he is frequently shedding layers of the cocoon constructed by living in societies for years.

In this way, s/he often becomes a more naked and bald being than anybody. S/he usually sees, feels, thinks, speaks, and experiences more directly and honestly than anyone.

## **1.2. introduction**

This is a qualitative study to investigate the hospice palliative care workers' experiences of caring for people from various ethno-cultural backgrounds. The focal point of the study is the data gathered through qualitative interviews with six staff members from various professions, such as the doctor, two nurses and others at the palliative care unit at a Catholic hospital in Vancouver.

Vancouver is extremely rich in diverse ethno-cultures, languages, religions, philosophies, and life-styles.<sup>1</sup> This diversity challenges professional caregivers trained in North America to provide appropriate care for those who are dying. In hospice palliative care, every single word and action carries moral weight (Gunaratnam 1997; Whittaker 1997) and contributes to the patients' quality of life and death. One would expect this task to be even more demanding when the caregivers try to provide proper care for dying patients with backgrounds different from their own. Many of the concepts that have been key in the development of palliative care, such as quality of care, quality of life, and good death, are embedded in European and North American cultural contexts. Hospice palliative care for patients from other ethno-cultural backgrounds sounds complex and confusing. However, the cross-cultural encounters between palliative care professionals and their dying patients have received little attention.

Hence, the question this thesis asks is, "What are the experiences of the doctors, nurses, physiotherapists, social workers and others who provide care for the dying patients from other ethno-cultural groups?" Accordingly, the thesis examines how these experiences relate to the core or essence of hospice palliative care. More precisely, the paper addresses the following questions: Are there any differences for the hospice palliative care workers in providing non-medical care to the patients from other ethno-cultural groups?; Do cultural differences pose obstacles

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<sup>1</sup>Among immigrant groups, the Chinese are the largest with over 20% of the population of Vancouver; English and East Indian rank second and third. Other major ethnic groups are Scottish, German, Filipino, Italian, Irish, French, Vietnamese, Jewish, Japanese, Aboriginal, and Ukrainian. (Statistics Canada, 1991)

for the staff in minimizing the distress of patients whose cultural practices they may not understand?; and What strategies do caregivers use to communicate and care for people whose culture they do not understand?

These issues need to be addressed in order to improve the quality of care and quality of life for those who are from minority ethno-cultural groups, especially because equal access to hospice palliative care is guaranteed for all Canadians. (Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, 2000)

## **2. Literature Review and Theoretical Framework**

### **2.1. hospice palliative care**

This study concerns the development of the palliative care unit and its unique clinical culture. Hospice palliative care is not simply a division of health care; it also strongly influences one's dying process: the final and most important phase of one's life. In other words, hospice palliative care contributes to a more significant context of human life, namely, the psychological, social, cultural, religious, spiritual, and existential life of the patient, family, and friends. Thus, it requires a special framework other than the simple "cure-oriented" medical and health care model. The principles of contemporary hospice palliative care, as articulated by Cicely Saunders, consist of (1) pain control, (2) symptom management, and (3) inter/multidisciplinary approach to the total/holistic, physical, social, psychological, and spiritual pain and suffering of the patient. (Doyle, Hanks, and MacDonald 1998; Victoria Hospice Society 1998) Saunders, the founder of contemporary hospice palliative care, originally became a nurse, then a social worker and eventually a medical doctor. Saunders developed a new system of pain control utilizing narcotics and replaced the old concept of pain management which barely existed. In addition, she founded St. Christopher Hospice in London, England, the world's first modern hospice, in 1967.

Yet, the most important element is the philosophy of total/holistic care with the inter/multidisciplinary approach. The most influential figure in the formulation of this philosophy is the least expected kind of individual, a Polish Jewish immigrant patient, David Tasma.

[He is] a Polish Jew, an agnostic, who came from the Warsaw ghetto and had come over to England before the uprising [, who] was not very educated, ... referred to himself as 'only a rough old fellow', ... worked as a waiter[,] ... had no relations in this country and very few friends [, who] ... was only forty, felt his whole life had been wasted, and ... had inoperable cancer (Boulay1984, 54).

Tasma, a totally lonely stranger in a hospital in England, and Saunders, his social worker, became very close friends. Together, they discussed the kinds of care needed by dying patients. He provided her with the inspiration for the future of hospice palliative care.

When Cicely offered to read to David Tasma, thinking to comfort him, he said, 'No - no reading. I only want what is in your mind and in your heart.' She has never forgotten this simple reaction; mind and heart have become twin poles of St. Christopher's philosophy. The dying need the friendship of the heart - its qualities of care, acceptance, vulnerability; but they also need the skills of the mind - the most sophisticated treatment that medicine has to offer. On its own, neither is enough. (Boulay 1984, 172)

Hence, this man from a different culture helped her to crystallize one of the most important concepts in the development of hospice palliative care.

This dualism between the caring heart and the knowledge and skill of medical treatment is at the center of the hospice palliative care movement. From its beginnings in England, hospice palliative care has spread<sup>2</sup> throughout predominantly English-speaking countries in Western Europe, North America, and New Zealand and Australia as a response against an "increasingly scientific and technological medical system (Kearney 1996, 17)." The hospice palliative care model approaches this dualism by combining the medical model and "another way" in the current practice of hospice palliative care. Based on the medical model, the secure environment is created for the patient, family and friends by a multidisciplinary palliative care team. At the same time, the staff members are aware of the limitation of the medical model in the face of suffering and of the fact that there is "another way":

a continuing to care and to do all ... to minimize distress; a valuing of human relationship, of presence and of caring physical contact and an ability to acknowledge as carers the painful feelings of impotence and outrage in witnessing another's suffering without having to act on them ... [and ;] a trusting that time and something within.(Kearney 2000, 14)

To a certain degree, the medical model is effective for the physical aspect of all the patients. The care in "another way" is more difficult to accomplish for the patients from other ethno-cultural backgrounds.

## **2.2. liminality and communitas**

The academic and health care literature have not successfully addressed the issues of non-medical hospice

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<sup>2</sup> In the past twenty-five years the principles of treatment and care which were developed within this movement have begun to be integrated into mainstream western medicine and have led to the international dissemination of this new, yet old, health care specialty now known as 'palliative care.' (Kearney, 1996)

palliative care or “another way” for ethno-cultural others. The most common approach<sup>3</sup> is to categorize and describe different kinds of cultural and religious beliefs, behaviours, customs and rituals related to death and dying (Johnson and McGee 1991; Kearn 1989; Leming and Dickinson 1985; Metcalf and Huntington 1991; Obayashi 1992; Parkes, Laungani, and Young 1997; Platt and Persico 1992; Reynolds and Waugh 1977). In the context of Vancouver particularly, only one book addresses the needs of the ethno-cultural groups, covering health care in general, but not hospice palliative care specifically (Waxler-Morrison, Anderson, and Richardson 1990). These brief overviews tend to oversimplify the issue for experienced professionals (Gunaratnam 1997). None of these works addresses the complicated nature of the issue, the combination of the uniqueness of hospice palliative care and the distinctive characteristics of cross-cultural experiences. Meanwhile, this section attempts to construct, based on the liminality and *communitas* theory by British anthropologist Turner, a theoretical framework which does appropriately meet these requirements. Other elements and theories are also necessary for the theoretical framework to be more applicable and appropriate. In particular, Kearney’s “inner healer” and “work persona” models, considered a new theory in the field of hospice palliative care, are introduced in order to apply the anthropological theory dealing with socio-cultural phenomenon in general to a more specific field, the experience of palliative care workers.

Anthropological studies of death and dying have taken several different approaches to examine the relationship between society and an individual’s death (Justice 1997). These studies have addressed four major issues in this field: (1) funeral rites (Danforth 1982; De Coppet 1981; Hertz [1909] 1960; Malinowski 1929; Mandelbaum 1965; Radcliffe-Brown 1964); (2) death behaviour and cultural value system (Bachofen 1967; Bloch and Parry 1982; Hertz [1909] 1960; Humphrey and Zimpfer 1996); (3) the relationship of social and biological death in western societies (Glaser and Strauss 1965, 1968; Sudnow 1967; Watson 1976) and in many other societies (Basedow 1925; Cannon 1942; Counts and Counts 1985, 1990; Davis 1988; Eastwell 1982; Glascock 1983, 1990; Keesing 1982; Lachman 1982-83; McKellin 1985; Rivers [1926] 1978; Scaletta 1985; Warner 1937); and (4) dying process as transition (Armstrong 1987; Hertz [1909] 1960; Hockey 1990; McKellin 1985; Rivers [1926] 1978;

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<sup>3</sup>Another group of studies is done to quantitatively investigate the minority population’s access to the hospice service in USA and UK and indicates its lower rate consequently. The results of these studies do not totally apply to the Canadian situation due to the differences in the health care systems and social contexts. (Brenner 1997; Gordon 1996; Smaje and Field 1997)

Turner 1967; Van Gennep 1960).

The concepts of liminality and *communitas* originate from the rites de passage model by Gennep,<sup>4</sup> consisting of separation, margin or limen, and reaggregation stages, and then are highly elaborated on by Turner in the tradition of the British Social Anthropological school. First, the term liminality generally refers to the status of betwixt-and-between structural positions or status. One is in liminality during the transition from one place to another or one status to another. Liminality is originally defined to delineate the mysterious nature of the second of the three phases of the rites of passage “margin or limen” stage, where a real or symbolic threshold exists between the two distinctive statuses (Turner 1974). Turner further extends the definition of liminality to “any condition outside or on the peripheries of everyday life ... [and] often a sacred condition (Turner 1974, 46-7).”<sup>5</sup> This wider and more general interpretation of liminality, Turner asserts, can be applied to various socio-cultural phenomena besides typical rituals and rites.

In this liminal phase, according to Turner, people often experience *communitas*. *Communitas* is well described from two perspectives: *communitas* as egalitarian, holistic and direct human relationship, and as anti-structure,<sup>6</sup> which has deconstructive or levelling and stripping nature. First, *communitas* involves relationships that are homogeneous, “undifferentiated, equalitarian, direct, nonrational (though not *irrational*), [and] I-Thou or Essential We relationships, in Martin Buber's sense (Turner 1974, 46-7).” In other words, *communitas* is the relationship between individuals based not on social roles or status, but on the existential or integral ground of

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<sup>4</sup>The Van Gennep's concept of *rites de passage* is widely applied to the death and dying field in two ways: in analyzing the disposal process of the body (Bynum 1973; Clark 1982; Danforth 1982; Metcalf and Huntington 1991; Turner 1969; Walter 1990) and the bereavement process (Littlewood 1992, 1993; Walter 1991). Yet, Froggatt claims that this model is also useful to explore both the experience of the dying people, changing status from alive to dead, and the hospice palliative care context itself, i.e., the time and space where the boundary of life and death diffuses (Froggatt 1997). Lambek emphasizes, furthermore, that this model captures not only the experience of the individual, but also the entire human relationships surrounding the individual (Lambek 1981). Hence, the rites of passage model is suitable to investigate the experience of the dying patient and of the surrounding people, and the hospice palliative care context itself.

<sup>5</sup>However, social scientists criticized that Turner's view of liminality as too simple to apply to most of the complex cultural phenomenon in post-modern societies (for instance, Cheal, 1988). Yet, one of the few cases in modern society where liminality is obvious is the threshold between life and death Froggatt 1997).

<sup>6</sup>The “anti” is here only used strategically and does not imply a radical negativity ... (rather) something positive, a generative center. (Turner 1974)

human being. Secondly, Turner uses *communitas* to refer to the antistructure in relation to structure [see more on structure below]. *Communitas* or antistructure “transgresses or dissolves the norms that govern structured and institutionalized relationships and is accompanied by experiences of unprecedented potency (Turner 1969, 128).” In short, *communitas* or antistructure is “the fons et origo of all structures and, at the same time, their critique (Turner 1974, 202).” I will contend that these two aspects of *communitas* are presumed to be a shared experience among those who are in the context of hospice palliative care.

In a different vein, Turner contends that *communitas* also could relate to the marginalized status or position as well as the low and weak one (Turner 1969). He alleges that *communitas* could be experienced not only in liminality, but also in social marginality and in inferiority: “*Communitas* breaks in through the interstices of structure, in liminality; at the edges of structure, in marginality; and from beneath structure, in inferiority (Turner 1969, 128).” Thus, those who are marginalized and/or inferior in the society could symbolically represent the antistructured *communitas* as do those in liminality. Furthermore, Turner claims that the experience of encountering the marginalized and/or inferior could produce *communitas* (Turner 1969).

Thus, these two conceptualizations of *communitas*, as a stage in structured social relation and as social marginality, come together in the study of cross-cultural hospice palliative care. First, hospice palliative care is considered the context of transition from life to death, and from this world to another. Due to this nature of liminality, as Froggatt suggests, *communitas* is one of the major characteristics of hospice palliative care (Froggatt 1997). The second sense of *communitas* can be regarded as the major attribute of encountering with strangers or people from outside as well as lower-status people. The patients from other ethno-cultural groups usually belong to the former category and often to the latter category. In this way, the theory of liminality and *communitas* grasps both aspects of cross-cultural hospice palliative care.

Meanwhile, there is another dimension in the concept of *communitas*. *Communitas* or antistructure solely cannot form society or human life without structure. Turner defines structure as the other model for human relationship and relatedness<sup>7</sup> as well as a cognitive system.<sup>8</sup> In other words, all sorts of contexts, phenomena, and

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<sup>7</sup>The structural human relationship is “a differentiated, culturally structured, segmented, and often hierarchical system of institutionalized positions” (Turner 1969, 177). Hence, structure “holds people apart, defines their differences, and constrains their actions” (Turner 1974, 47), and “produces distance and inequality” (Turner

relationships in human life and society have both structural and communitas or antistructural aspects for connectedness and cognitive system. This balance between structural and communitas or antistructural dimensions varies according to the context.<sup>9</sup> Regarding these situations, Burrige defines the aspect of human being apparent in the structural dimension as “person [animal and sociocultural parts of self]” and the other aspect dominant in the communitas or antistructural sphere as “individual [profound part of self]” (Burrige 1979). While communitas connectedness, antistructural cognitive system, and/or “individual” aspect of self are the distinctive features of the context of hospice palliative care, structural relationship and cognitive system and/or the “person” aspect of self are, therefore, also recognized.

The dualism of communitas or antistructural and structural modes of human relationship and cognitive system, and that of “individual” and “person” aspects of self in the hospice palliative care context, significantly overlap with Kearney’s “inner healer” and “work persona” models which delineate the nature of the health care professional working in the hospice palliative care environment. Kearney claims that the self of the hospice palliative care provider consists mainly of two components, “inner healer” and “work persona”. The “inner healer” means “the inner, hidden, deeper aspects of ourselves as carers (Kearney 2000, 15).” It is associated with “the more mysterious workings of the unconscious ... [and] the intuitive, symbolic, and lateral-thinking function of the right brain (Kearney 2000, 15).” On the other hand, the “work persona” is “the outer, visible aspect of our working self (Kearney 2000, 15).” It is related to “normal ego-functioning within the conscious mind ... [and] the left-brain functions of logical and analytical thinking (Kearney 2000, 15).” Kearney emphasizes the importance of proper balance between “inner healer” and “work persona” in order to practice sound hospice palliative care.

Therefore, the experiences of those who are in the hospice palliative care context are considered more

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1974, 272).

<sup>8</sup>Turner also points out that structure has cognitive, linguistic, and ideological aspects. In this sense, structure “confers order and regularity on phenomena or assumes that these will be found in the relations among phenomena” (Turner 1974, 287).

<sup>9</sup>For instance, in the secular sphere of the society, the structural aspect is more visible and the antistructural or communitas becomes less obvious. On the other hand, those who are in the sacred space experience more communitas or antistructural side than structural.

antistructural or *communitas* than structural.<sup>10</sup> The “individual” side of self is supposed to appear among people in the hospice palliative care context more than “person”. The “inner healer” is presumed more dominant than “work persona” in the awareness of staff members in providing palliative care. In particular, these tendencies are assumed more evident in the context of cross-cultural encounter, in this case, providing palliative care for the patients from other ethno-cultural groups. While theoretically this is the case, this issue still needs to be explored in the reality.

### **3. Research Design**

#### **3.1. context**

This study was conducted in a palliative care unit<sup>11</sup> (hereafter PCU) with staff who are very experienced in practice and progressive in the delivery of care in a Catholic teaching hospital located in the extremely rich multicultural context of Vancouver. This ten-year-old, 15-bed palliative care unit is located on the top floor of the hospital building. Within the hospital itself, the general impression of the unit is that everything and everyone contributes to making the atmosphere as homelike as possible. The unit creates this atmosphere in three ways: visually, structurally, and organizationally.

The visual aspect is a simple, but most effective means of producing this homey and cozy mood. Paintings, pictures, flowers, plants, and stuffed animals donated by families and friends are seen throughout the unit. The common themes are nature, scenery, animals, portraits of past patients, and angels. Together they create a calm, warm, and soothing almost spiritual impression. All staff members in the unit wear street clothes, unlike the lab coats and other uniforms worn by other hospital staff. House-keeping staff and unit aids, however, wear uniforms to protect their clothes. Patients are encouraged to wear their own clothes whenever and wherever possible instead of hospital gowns and to do whatever they like to do. Usually, there are many family members and friends visiting at all times of day. In this way, the unit visually maximizes its home-like environment in the institutional atmosphere of the modern tertiary care hospital.

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<sup>10</sup>Meanwhile, some studies depict the institutionalization, routinization, bureaucratization, and secularization of hospice palliative care. (Bradshaw 1996; Charlton 1992; McNamara, Waddell and Colvin 1994)

<sup>11</sup>The unit also has a home care team. However, the home care team is excluded from this study.

Secondly, the architectural also structural aspect of the unit contributes to the home-like ambiance. The unit has 15 beds in total and consists of one four-bed room, one three-bed room, two two-bed rooms, and four private rooms, each of which has its own bathroom. Each bed has a small storage space, movable table, curtain, sphygmomanometer, nurse-call bell, oxygen inhaler built to wall, and light. Usually, the patient, family, and/or friends decorate the area around his/her bed with cards, pictures, paintings, flowers and stuffed dolls in order to create his/her own personal atmosphere.

The unit also has three rooms for public use. There is a room with a couch and a hide-a-bed sofa with a full bathroom, which is used for family or friends to stay in and to have a casual meeting with staff members. A small lounge has sofas, chairs, recliners, plants, a pay phone and magazines. It also has a non-smoking balcony with chairs. This lounge was recently named the "origami (Japanese paper craft)" lounge because it has a lot of different kinds of origami pieces hanging from the ceiling which are sent yearly by a Japanese woman from Japan whose friend died at the unit years ago. This room is mainly used as meeting space for, for instance, family meetings. The lounge is also used as a temporary private room when a patient and family need privacy due to the fact that s/he is actively dying in a two- or four-bed room. It is also a place for family and friends to stay. A bigger lounge has a TV, VCR, stereo, small music tape library, small book library, piano, toys for kids, puzzles, games, cards, plants, and chairs and sofas. It has a bathroom and a smoking balcony. It is next to a small kitchen for patients and relatives with a refrigerator, microwave oven, coffee maker, electric kettle, small sink, dishes, glasses, mugs, glasses, teapots, western utensils, tea bags, sugar, packs of jam, peanut butter, honey, and cookies. This lounge is primarily a socializing space. For instance, every other Monday night, various musicians are invited to perform concerts for patients, families, and friends in the room. Another example is that patient, family, and/or friends usually come to the lounge to have a chat, tea, coffee, lunch, or dinner together as well as to watch TV or videos.

The rest of the unit consists of the nursing station, offices such as the doctor's, pastoral care worker's, social worker's, and volunteer coordinator's, staff room, two meeting rooms, staff kitchen, laundry room, and storage room. This area is constructed functionally in a very similar way to the rest of the hospital. The nursing station, the central nerve system of the unit, monitors and manages the whole unit. All the information, all the admissions and discharges, and all the staff members go through the nursing station.

Finally, the organization of the staff also helps to maximize the homey and cozy tone of the unit, while effective palliative care can be systematically and strategically provided. The unit has the inter/multidisciplinary team consisting of 5 GP (general practice) doctors specializing in palliative care, 1 male and 4 females, dozens of RNs<sup>12</sup>, a patient care manager, a few pharmacists, allied workers (1 music therapist, 1 occupational therapist, 1 physiotherapist, 1 social worker and 1 pastoral care worker), unit coordinators, unit aides, housekeepers, a volunteer coordinator and dozens of volunteers. These specialized personnel complement the oncologists, hematologists and interns who often visit the unit. Generally, most of the staff, besides the volunteers, tend to stay in their positions in the unit for more than a few years. The majority of the staff are female. The essential impression the staff try to convey is that they are a big family or a small community. This includes the many volunteers whose number is exceptionally large compared to the rest of the hospital.

The most noticeable characteristic regarding these staff members is that, compared to the rest of the hospital, they have more time for each patient. No matter what position and job title s/he has, each of them spends considerable amounts of time sitting down and talking with patients and/or family members and/or friends, answering questions, comforting, or socializing. Meanwhile, various professionals play their roles based on their job descriptions in the context of the inter/multidisciplinary team approach.

Doctors are in charge of directing pain control and symptom management as well as managing admissions and discharges. Nurses provide most of the patient care, such as giving medication, feeding, giving baths, changing, and making beds. Pharmacists supervise the medication prescribed by the doctors to treat disease and relieve pain and other symptoms. A music therapist plays an electric piano and sings by the bedside or in the hallway, providing music tapes and CDs along with CD/tape players for the patient's personal use as well as organizing Monday night concerts. An occupational therapist helps to maintain necessary skills for the daily life and arranges tools to help patients to live more independently, such as walkers, wheelchairs, and scooters. A physiotherapist does physical rehabilitation to sustain the basic body functions, such as walking, sitting, and breathing, as well as provides massage. A social worker mainly takes care of the social and psychological aspects of the patient's life, from helping

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<sup>12</sup>Some nurses had obtained diplomas in palliative care on scholarship mainly provided by donation from patients and relatives in the unit.

to deal with financial matters, to contacting patient's family members and friends with whom the patient wishes to make contact, to finding interpreters, and to providing family/group as well as individual counselling. A pastoral care worker is mainly in charge of the spiritual and religious needs of the patients and families, such as assisting in the arrangement of funerals/memorial services and offering spiritual and religious support. Unit coordinators administrate all the information, for example, by accessing the computer system, filing, and answering phone calls; housekeepers clean up and unit aides do supplementary jobs. A volunteer coordinator recruits, interviews, trains, and manages volunteers, who are ordinary people with over 30 hours of training and come once a week for 3 hours and who do everything else to make the patients, family members, and friends comfortable, such as providing company for, listening to, talking with, making coffee, tea, and snacks for, walking together with, and shopping for them.

Time is organized similarly in the unit to the rest of the hospital. Yet it is, generally speaking, quieter, calmer and more peaceful than the rest of the hospital. The staff and patients are busier during the week than on the weekend. The majority of the patient admissions and discharges occurs during weekdays. There is also a clinical round meeting to discuss medical, psychological, social and other issues of each patient twice a week, on Tuesdays and Thursdays. Family meetings are usually held during the week as well. Hence, the unit has more staff members during the week while the staffing goes down to the minimal, essential level, including doctors, nurses, unit coordinator, and housekeeper, on the weekend. Besides these weekly routines, the unit provides a bereavement program a few times a year. It is organized by a social worker for the families and friends of the patients who have passed away. As well, the unit's collective memorial service is administered by a pastoral care worker, social worker, music therapist, volunteer coordinator, volunteers and other staff members every four months.

The socio-economic backgrounds, as well as the ethno-cultural backgrounds, of the patients vary considerably reflecting Vancouver's multicultural population. The majority of patients have cancer or AIDS with a less than 6 months prognosis. While the age of the patients varies from over 20 to over 100, the majority are older patients in their 50's, 60's, 70's and 80's. The proportion of male and female patients is almost equal. Some of them come to the unit for respite care for a few days to a few weeks and go back home. Others come to the unit from hospices and other units such as extended care and oncological units in order to obtain more advanced pain control.

In both cases, many patients end up staying in the unit longer than they planned due to complications and progression of their condition. Many patients go to hospices from the unit after their pain and symptom management is under control. Others die on the unit. In summary, each patient is unique due to the fact that s/he has different medical conditions such as diagnosis, prognosis, symptoms, and pain, along with individual non-medical situations, such as ethno-cultural and socio-economic background, and psychological, emotional, spiritual and religious issues.

On the unit, the patients are encouraged to live the way they live in their home as much as possible. As long as a patient does not bother other patients, s/he is basically allowed to do whatever s/he wants. For instance, patients like to watch TV, listen to music, smoke, have tea with family or friends and go out for coffee, lunch or dinner with them. The family and friends of the patient are exceptionally important in order for the patient to live fully until s/he dies,<sup>13</sup> clearly because they are one of the most essential components of the patient's life. In addition, a patient befriends another patient, staff member, and/or family member of another patient through his/her stay in the unit. Sometimes, the friendship or connection between the patients is extremely significant, so that they call each other "my spiritual sister or brother" or "my true friend," for instance. In this way, this aspect of the patient's life is maximized even in the modern tertiary hospital environment.

In summary, the unit appears to be something between a modern tertiary care hospital and home, visually, structurally and organizationally. The elements of the modern hospital environment are visible while at the same time the effort to produce the homey and cozy atmosphere is apparent. Furthermore, the functions of the modern acute hospital are maintained in the unit's physical structure; simultaneously, the unit has plenty of room to maximize the social space for the patients, families and friends. Most importantly, a patient as well as a health care professional act in both the care giver-care receiver relationship and in the friendship or family relationship. A patient is encouraged to live the way s/he likes, often involving his/her family and friends, while s/he receives the care from the palliative care team. A staff member provides both professional care, and companionship and friendship. This characteristic of the unit, betwixt and between hospital and home, reflects the deeper layer of

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<sup>13</sup> Meanwhile, some patients prefer to be alone.

hospice palliative care. Most interestingly, the unit, the liminal space, is symbolically marked<sup>14</sup> at the entrance, emphasizing the boundary between the unit, the liminal space and the outside, the modern acute hospital. The marker of the boundary includes a painting of a guardian angel. The marker at the entrance consciously or unconsciously reminds those who enter the unit, in particular the staff members,<sup>15</sup> of the liminal or sacred nature of the unit.

### 3.2. methodology

The research included interviews developed from my experience as a long term volunteer in the unit. The interview participants were professional staff members whose work mainly involved contact with patients and relatives, and who participated in the clinical round meeting to discuss patient cases with other members, such as physician, nurse, social worker, pastoral care worker, occupational therapist, physiotherapist, and music therapist. These one-hour, semi-structured interviews with open-ended questions were tape-recorded and transcribed. The interviews addressed two major points: (1) why and how an interviewee has become a staff member at the Palliative Care Unit, and (2) their experiences caring for patients from other ethno-cultural groups.

The interviews were carried out according to the following procedure: (1) A letter briefly describing the study was posted in the communication book to which every staff member had access. (2) A potential interview participant contacted me in person to inform me of her/his interest in participation. (3) A letter which described the study further was given to the potential participant. (4) A potential informant made contact with me to make an appointment for an interview. The time and location were considered for the convenience of the informant. In particular, the location was carefully chosen considering the privacy and confidentiality of the interview participant. For example, it was a quiet, isolated and comfortable place. (5) The interview started by obtaining the participant's

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<sup>14</sup>The decoration of the unit's entrance reflects Gennep's description of the boundary between sacred and secular places (Van Gennep 1960). Also, Kuhl describes the profound impression of the sacredness by quoting as follows:

When the Lord saw that he turned aside to look, God called to him from the midst of the bush, and said, "Moses, Moses!" And he said, "Here I am." Then he said, "Do not come near here; remove your sandals from your feet, for the place on which you are standing is holy ground." *Exodus 3:4-5*

New American Standard Bible (Kuhl 1999, 1)

<sup>15</sup>A staff member usually stops at the entrance to read the cards in order to know who has passed away while s/he has been away from the unit (for hours and days).

consent.

The interviewer was a Japanese male from Japan who had been in Canada for 6 years doing academic work and volunteering in this field. Meanwhile, six staff members, named “U”, “V”, “W”, “X”, “Y”, and “Z”, participated in the interviews. They were all Caucasian females consisting of one doctor, two nurses, one physiotherapist, one social worker, and one music therapist. Two of them were in their thirties, one in her forties, two in their fifties and one in her sixties. The number of years they had worked in the Palliative Care ranges from two to ten years. The demography of these interviewees approximately reflected that of all of the PCU staff members. Different locations were selected for the interviews by the participants: two chose their offices in the hospital; one chose another room in the hospital; one chose her house; one chose a coffee shop; and one chose the interviewer’s apartment. The time of the interview was one hour on average, forty minutes for the shortest and one hour and a half for the longest.

After all of the tapes were transcribed, the transcripts were carefully read through several times to extract common themes. All parts of the transcripts were labelled and sorted into the groups with the common themes. Each common theme group was thoroughly examined to probe intra- and inter-group relations. These procedures were repeated several times to achieve further clarification and deeper understanding of the data. Then, the common theme groups were organized with more comprehensive categories to be presented in this thesis.

#### **4. Data**

After the interview tapes and transcriptions were thoroughly analyzed several times, four main themes appeared: (1) the staff members’ perspectives on culture, (2) family, (3) verbal communication, and (4) communication and interaction without or beyond language. This chapter delineates these themes in detail and in depth by utilizing the direct voices of the interviewees. The first part of the chapter illustrates the staff members’ general ideas of (ethno)culture as the ground framework for the rest of the chapter. The following parts of the chapter describe more practical and actual issues regarding care for the ethno-cultural others.

##### **4.1. staff’s perspectives on culture**

This section discusses four issues regarding the staff’s conceptual framework which served to define culture: (1) what kind of cultural background the interview participants had before they started working in PCU; (2)

how complex and confusing the concept of culture is for them in providing palliative care; (3) how people are viewed as essentially the same regardless of culture; and (4) the primary and secondary issues in providing palliative care for patients from other ethno-cultural groups.

#### **4.1.1. cultural background of staff**

While growing up in different times and places, the interview participants had various influences to shape their perceptions of other cultures. Some had very homogeneous environments at home and/or at school when they grew up, as “X” explains: “I grew up in a very racially homogeneous white background, and it was also during the war.” Others had very multicultural ones, as in the case of “W”:

I was brought up in a family ... where my parents were very open and welcoming to all colours, all religions, everything. And my mother and dad were working class people .... I think because of their exposure in life and their treatment in life, they became advocates for people. Because they were treated with such disrespect, so from them I learned to be respectful for all races and all religions.

Some others had a combinations of both types of environments. “U” has been very familiar to cross-cultural perspective since her childhood.

My parents are both from other countries and are pretty well traveled. We had people come over to our home from different parts of the world. And I have always loved traveling myself, so I think I am very open. I also love languages, so I studied modern languages. I want those tools to speak to people of other cultures, I think there were a lot of things from my family life that made me open to different cultures.

While exposed to different cultures and people at home, she had different experiences at school.

In my elementary school, ... it was very WASPY and a very WASP culture. My high school was quite different. I went to a high school deliberately where it was quite different from what I had been in before. I wanted a change from the friends that I had. I wanted a different group of people to mix with.

One way or another every participant had had some sort of exposure to other cultures before working at PCU. They had expanded their horizons to experience new things and people and shaped flexible, open attitudes towards different cultures sometime in their lives. To some degree, in other words, the ground for their views towards cultures had already been formed.

#### **4.1.2. culture as a complex concept or an illusion**

I was particularly concerned with the staff members’ understanding of “culture” or ethnicity. All of the interview participants indicated confusion and complexity surrounding the concept of culture, in particular ethno-culture. Many pointed out the gap between socially-constructed stereotypes of other cultures and actual experiences

with patients and relatives from other ethno-cultural groups. They claimed the description of other ethno-cultural groups in books is too simplified and stereotyped to apply to any actual situation; as "V" mentioned, "it is not as black and white as that." They emphasized how diverse the characteristics of any ethno-cultural group can be. For instance, "X" explains how varied Chinese immigrants, the biggest ethnic group in Vancouver, can be:

If you're talking about the Chinese community. If someone came here from China, their family came here from China in 1858 when people first came to British Columbia; they're going to have very different perceptions of what is appropriate around death and dying than someone who came from a northern province in the last month, or Hong Kong when it reverted back to China. They will all have very different perceptions, some will be westernized. And I think there are different perceptions in China itself about different issues around death.

Additionally, she raised an example to describe variations in cultural practices of the First Nations people.

I have spent quite a bit of time with the native people up and down the coast, and they all have very different traditions and culture. Some of them have been impacted by contact with the Europeans and some revert back to the older ways, but they're all colored by their experience. But there's no one way, you know, the issues around dying. I remember one woman in our bereavement program and her brother had died near the Yukon border. Everything was packed away and there was a feasting and a celebration of his life. Then a year later his clothes were given away and that would lighten his burden so that he could cross over to what they call the other side. Other people will take the belongings of someone, other bands and they will be burned, so that in some sort of changed way they go up in smoke and are available for the journey. So everybody does it a little bit differently.

The interview participants all agreed that each case with a patient from another ethno-cultural group is very unique, as "V" commented: "Each death is very individual. No two deaths are alike."

How are they managing these confusing and complicated matters? They have learned a simple, but effective way of addressing these matters from their experiences. First, they are strongly cautious about the stereotypical expectations of the other ethno-cultural groups, as "U" stated:

I think the first thing is never to set up expectations because of someone's cultural background, from what you read in the paper and what it says about where they are from. It may not have any impact that you expect, it may have a huge impact in terms of the kind of care you are going to give. So, despite being in any one particular cultural, ethnic, or religious group, you need to meet that individual for who they are and how they are.

Their consensus is that they meet a patient as a unique, individual person with as much of an open-minded attitude and with as little of a stereo-typical expectation as possible. Then, their next step is simply to ask the patient any questions if they do not understand something. In particular, they emphasize addressing the patient's needs and important issues relating to their cultural background, which are often overlooked due to the gap between the

stereotype and reality, as “X” mentions: “I find the best thing to do is to ask before what’s important to them.” At the same time, they attempt to eliminate their own biases and agendas and to know the patient’s perspective based on her/his cultural background: “If I don’t understand their culture, I ask what do you need, not what do I need. ... So you have to find each individual’s needs (“W”).” In other words, they try to give power to the patient, not to the health care providers.

There is no better way to summarize and conclude this section than by quoting the comment from “Y”:

What is it the culture of that particular family? Because every culture is different no matter what’s their ethnic culture...on top of that their ethnic background and any spiritual basis that they have. It can be so complex. You can have two people from the same ethnic background that have different religions. So the same rules don’t apply to that situation. You can have people from the same ethnic background with a different family culture. So the same rules don’t apply to that situation either. So in a sense I think that the one thing I have learned is that there are no rules. There is no one way to do anything, based on any culture or family belief system. We just have to be as open and willing to learn as where people are at, and what’s helpful for them at any given time. That may change from one day to the next. I think that in respect to culture, it is very helpful for us as individuals to know as much as we can about different cultural beliefs around dying and different spiritual beliefs around dying .... So for me personally, being as open as I can and as willing and wanting to learn, that’s the most helpful.

#### **4.1.3. universality and commonality rather than cultures**

While depicting the differences, many participants emphasized that people are essentially the same despite all the ethno-cultural differences. They claimed that all humans are the same in terms of the common ground of human beings as well as of the process of dying. First, they strongly believed that there is a universal ground shared by all human beings. Once “getting down to the humanity level (“V”),” they explained, “there is no difference .... It doesn’t matter if you are white, black, green, red, yellow, a drunk, an alcoholic, whatever label they put on you, you are one (“W”).” “Y” addressed this common ground by discussing “spirituality”. Through her life, she gradually “became aware of a certain sense of spirituality without necessarily a religious label of any sort.” She continued by saying that people are all the same and, therefore, can connect and communicate:

It’s my belief that we are all the same. Whatever our belief system or spirituality, whatever works for us to put it in a framework, I do believe that it’s all the same thing and that’s my fundamental belief that we are all the same and we find our way to the sense of self and spirit... whichever way it fits for us but that we are all about the same thing. So that in a way we can all connect at the heart and soul level without language and without culture.

Secondly, two participants pointed out that all human beings are the same due to the nature of the dying process. In the dying process, the cultural aspect of the person becomes smaller. “V” explained this by comparing

death to birth, "It's just a revelation that you come into this world naked not knowing a language and just being without ethnic, cultural influences and, as you are dying, you are shedding all your ethnic cultural differences and coming right into the core of your spirituality as you approach death." She continued, "if you're born naked, you die naked. You're born without outside influence and at death there are no outside influences." Hence, all human beings are the same in the face of the dying process in spite of ethno-cultural differences.

#### **4.1.4. primary and secondary issues regarding culture**

As discussed above, the staff's perspectives on culture, which are mainly formed by working in the unit and partially influenced by their cultural background, have two different points: (1) how diverse people are within the same ethno-cultural group; and (2) how similar people are across cultures. The obvious question here is how these are related in their perspective. Do these conflict with each other? Is one a necessary condition for another? Or, are these two aspects of the same phenomenon? This interview could not investigate the conceptual framework of the majority of the participants to explain the relationship between the two points. Only "V" provided her opinion regarding this issue in terms of providing care in the practice. She referred to various cultural practices relating to food, hygiene, and ritual as the secondary issues in practising palliative care. These issues are rather easy for her to deal with, as she explained,

With the First Nations people if they want to come in and have a drumming ceremony etc. we'll arrange that. That's not a big deal at all. Yeah, these are...like secondary...food issues are secondary to us. We can always work around that .... We try to be as accommodating as possible for people we know trying to get the foods that they like and music that they like and whatever else that will make them feel more comfortable in the whole dying process.

Then, the primary issue for her is the spiritual component of the patient. As discussed in the previous section, "V" defined the core of human existence as pure spiritual being. The ethno-cultural and social characteristics are the outer layers of the individual.

#### **4.2. issue one: family**

Ethno-cultural issues become most apparent once family is deeply involved in the care. In other words, family is considered the most obvious evidence of cultural difference. The family is regarded as the essential part of palliative care in general. The families are much more involved in the cases of the patients from other ethno-cultural groups. For instance, when "Z" was asked about the ethno-cultural issue, the first thing that came into her mind was

a family at an airport.

White Anglo-Saxon, some Ontario people are not known for tolerance or being welcoming for things that are different. So you know, the airport is an example .... So when the Italians go to the airport, the entire extended family will go. There's a crowd of people and you know the sort of cultural group I was from will say, "why do all these people have to be here?" You know with this ... they'd make it very chaotic. But it was part of a way of life compared to a typical Anglo-Saxon/British kind of background ... where everyone is proper and not making a fuss and all that kind of thing. So naturally that was my first experience with culture.

This example epitomizes the discussion in this section: quite frequently "the entire extended family will go to the hospital and they'd make it very chaotic." Then, those with "a typical Anglo-Saxon/British kind of background ... where everyone is proper and not making a fuss" might ask, "Why do all these people have to be here?"

In this section, the family issue is investigated in terms of the decision-making process, communication style, and autonomy.<sup>16</sup> The discussion will focus on first, who the decision maker is; second, the patient- and the family-centered approaches; third, the issues regarding children; and finally, the depiction of the pitfalls experienced by the staff members.

#### **4.2.1. who makes a decision?: patient vs family**

The decision-making issue is the most significant concern according to the interviewees. If families become involved in care and decision making, the cultural aspects of family relations and assumptions about personhood and care become a concern of the staff members. Clearly, they experienced conflicts and frustrations due to the different decision-making practices among the patients and relatives from other ethno-cultural groups. "V" recalled a recent case of a patient who lived in Canada and withdrew from his ethno-cultural community for a while:

An example is a man who just died recently who had no immediate family, but his own personal wishes were within a will and we upheld that will, whereas his community was battling what we were trying to do for the patient. They were very confrontational as to his care, etc. So, there again, we just tried to uphold the patient's autonomy even when he was unconscious and unresponsive. We ... tried to uphold his autonomy and his wishes as outlined in his will. Even though the community itself was pressing us to do things their way. There was a lot of conflict and a lot of staff burnt-out at that point because the community was huge and they were always there. It was really draining. It's sort of an ethical thing, what does the community want versus what the autonomy of the patient is. Of course, the focus for us was the patient autonomy. I don't know to say whether it's right or wrong with certain ethnic groups, but if a patient has

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<sup>16</sup>"V" explains other example regarding this family issue:

That's when we come into ethical dilemmas in PCU. Like keeping a dying patient on IV, which is a futile intervention but the family wishes to keep the family member who is dying alive beyond a certain date. Things like that, it's just a matter of us remaining open-minded to different cultural practices, so that we can be respectful of cultural differences.

certain wishes, as staff members, that's what we follow through on or try to follow through on as best we can.

This is an extreme case which illustrates how severely the different views towards decision-making can influence the staff members. Usually, similar situations have common elements, but are less extreme. When the patient's and relative's (usually the immediate family) wishes conflict, "Z" explains, the staff members ask for outside help:

If it was a really big gap between the two points of view, we will probably involve a third party, or we might get the ethics people involved, or have a discussion with the family. Sometimes we use the moral and ethical grid with the medical considerations and what the patients want and what they need and what their contextual features are. And so the family will then be involved in giving input to various quadrants and then collect [inaudible on tape] and come up with a decision.

There seems to be no clear guidelines or procedures to address this issue. If there is any strategy, it is to be case-by-case in each situation.

So, who makes a decision, the patient or the family? That is the question, although it is a very difficult one.

There are two opinions among the interviewees.

#### **4.2.1.1. patient-centered approach**

Some consider that the patient as an individual is the focus of care. For instance, "V" discussed this by using well-recognized medical-ethics words, patient's autonomy and wishes:

the patient's autonomy and patient's wishes are always the focal point, and that's usually what the disagreements and discussions are all about. The first and foremost priority on PCU is what does the patient want, how does the patient want to die. That's what we try and uphold through their last breaths. It might not be good for the family because it may cause more conflict but that's part of the whole process, the patient always remains number one.

...  
The patient dies with dignity and within the realm of what their last wishes are. There again as a team if we were to discuss what was going on with the patient versus what is going on with the family, it's going to be decided on an individual basis. I don't really have any answers, it would have to be open to discussion and we would all have to negotiate as to what's going to be the best all around for everybody.

Clearly, this approach often causes disagreements and discussions among the staff members. Some staff members may see their role as the patient's advocate, while the others are the family's. This kind of discussion does not appear to reach any satisfactory solution. Again, there are neither guidelines nor procedures. The only solution seems to be case by case.

Some of them seem to take the patient-centred approach for granted, including patient's autonomy. For instance, "Z" explained her view:

There's no question about that. It's the patient's decision that we'll go for. If a family member/family had a problem with it ... it's their way... now you are getting into guardianship. If the patient was [inaudible on tape] if you were to make the decision then you make the decision. It's not up to another person. It's only when the patient doesn't want to make her decisions that we have to consider getting the decision from another person.

The patient is the first priority and the family is the next priority for the staff members in her opinion.

Additionally, "V" felt that the patient-centred approach is unwritten rule at PCU. This rule is bent only when familial situations do not allow it, not when the staff members or others disagree:

Unwritten rules, yes. Well, basically unwritten rules that patient autonomy comes first. What the patient wants is what we strive for. Sometimes that does not work out. For example, if a patient wants to go home but the caregivers at home cannot and will not take care of that person, then there's nothing we can do in a situation like that. We cannot force somebody to take somebody on .... It's very sad and heartbreaking when that happens, but sometimes we are in a position where it's out of our hands.

While "V" claimed that the patient-centred approach is the unwritten rule in PCU, some others do not agree that this is always the case.

Thus, it is an individual choice for each staff member whether or not to take the patient-centred approach.

Yet, these interviews could not investigate their reasons for the patient-centred approach.

#### **4.2.1.2. family-centered approach**

The others stated that the family-centered approach is more appropriate for the patients from other ethno-cultural groups. While admitting that the patient should be the decision maker, "Z" stated that this does not always apply to the patients from Asia.

I guess the other thing we have certainly become more aware of in the Oriental cultures I have come across and sometimes especially for an elderly mother, the children or primarily the eldest son is the decision maker. And it's quite a different way of communication.

This different communication style and decision-making process stem from a different view towards a deeper element, i.e., patient autonomy. Comparing Western culture with other cultures, "Y" emphasized that there are different perspectives on patient autonomy while acknowledging the importance of the patient-centered approaches in Western culture:

We always go back to what are the patient's wishes because I think certainly in Western culture, autonomy is like the number one priority. It's certainly not in a lot of other cultures. In our culture autonomy is the big thing and what does the patient want and they have to make the decisions. It's very, very different in Muslim countries, lots of different countries.

The different communication style, decision-making processes and views on autonomy are major reasons for the staff

members not to always apply the patient-centered approach.

Here, the staff's concept of the individual cannot be applied to these patients. The only way to provide care is to treat the family as one "in-dividual" or inseparable unit instead of the patient as one individual person. For instance, "Y" argued how important the family is in the life of the patient from some ethno-cultural groups. Hence, care for the family is essential for the good care for the patient.

I do think that if we are able and we can develop a skilled enough team ... it is in the patient's best interest ... and it's the best care of the patient if we can address the family skillfully, too. Because they are left behind and we need to care about them too. You know that the patient's primary concern that this is their family and we need to care about their grief process because that impacts so many people and it can change the life of one of their children ... if it's done poorly and if it's done better.

Her point is that the scope of palliative care should cover the patient and family as well as include their present and future. In other words, the palliative care is likely to be stretched to include the family in the face of cross-cultural encounters. Thus, the family-centered approach requires palliative care to be more holistic and total. "X" addressed this point as follows:

I think that when you are working with people at the end of their life it's a privilege to be part of their life at that time. You have the opportunity to make a difference in people's lives. And certainly when working with families to help them – really it's teaching them how to support people who are dying and it's time for the family to be close and not time for the palliative team to take over the care. It's a time to centre the care around the dying and their family and support them as a unit. I really believe that it's more holistic in its approach than the medical model.

In the family-centered approach, the center of palliative care is the patient surrounded by the family. Then, the staff members support them as a unit which has its own autonomy, decision-making process, and communication style.

The family-centered approach seems to become problematic when conflicting with the core of palliative care protocol, i.e. death with dignity based on pain control and DNR. For instance, "Z" explained that a different decision-making process cause some difficulties,

It also makes it difficult for the team to feel that they can create plans for the patient. Sometimes the decision maker is not very readily available and perhaps not accustomed to making decisions so .... But again we have to go with what's right for that family. To me that's what we have to do. I mean that would be quite difficult with something like pain management for example. I think that would be a time when it's very hard for the staff to agree to say undermedicate the patient because some felt that it was wrong for the patient to receive anymore narcotics, for example. And I think that we have run into things like that, but they ultimately become resolved. There is a period of time, especially when pain is the issue, that's hard for the staff to watch a patient in pain and know that they could be made comfortable.

In this example, the cause of the problem is not only the different decision-making process. Different views towards

pain and medication as well as different attitudes towards family members seem to be more significant. However, these issues were not addressed by the interview participants in detail except for the children issue introduced in the following section.

#### 4.2.2. children

The interviewees pointed out that many patients and families from other ethno-cultural groups have different ideas about how their children should be involved in the family member's dying process. "Z" raised a few examples,

We did have a lady a couple of years ago, she spoke English fine. But she was very much of the Greek culture and she didn't want her young son to see her sick. As I recall, he seldom saw her. So that is not necessarily attributed to a particular culture .... Just between the last six months a younger Oriental woman who has young children seemed very reluctant to have her children see her in her declining state.

These mothers did not want their young children to see them when they were in a declining state. Yet, the staff member thought that they should be involved more positively and actively. "Y" elaborated this staff's view in another example.

We had an experience with a Chinese family who had children. And we had a belief that it's better for kids to know what's going on and to see their mother more and to be part of it. And that was our belief system ... coming from the work that we do and I don't know if that's right or wrong. But we were well-intentioned and we were trying to encourage this family to bring the children in more. But in their particular family culture and perhaps their ethnic culture it was just not done. They didn't feel that it would be a helpful thing. And we needed to understand that and maybe our approach could have been different in the sense of spending more time trying to understand what their way would be and what they think would be helpful and what they've done and what they'd like us to do. There was a language barrier as well and so it was difficult because we always needed an interpreter.

This gap between the staff and family appears to partially stem from the difference between death accepting and denying cultures. "Y" explained her reason to support the children's involvement in the family's dying process.

We hear about things that happen to people when they were young. You know, it often has to do with a death and grief and bereavement and how their lives have been impacted by not going to the funeral or not talking about it or ... usually it tends to be on the side of protecting ... and so not allowing them to process especially children. That's sort of my experience and my bias obviously.

Her bias seems to be that dying is a natural part of life and, yet, is often hidden for some human reasons. The more the dying is hidden, the more people are afraid of it. She continued,

But I do think that and I think that it's hard for each team member to be expected to be skillful at that because we are not all trained that way. But I think it's really important to have skillful means to address family concerns too because it's important and it can shape the lives of the people left behind and everyone else that they're in relationship with. It does affect the world, you know.

Ideally, the children are helped by the skilled staff to participate in the family member's dying process following the hospice palliative care's philosophy. The reality is far from the ideal situation and concerns her. She went back to discuss how important the family-centered approach is. Her hope was to widen and deepen the scope of palliative care to include the family, in particular younger members, the future and the world.

#### **4.2.3. culture as a pitfall for the staff members**

There are major pitfalls for the staff members providing care for the patient and family from other ethno-cultural groups. These are related to the preconception and/or stereotype of cultural differences and of particular groups. For instance, "Y" warned that it is dangerous for the health care providers to assume what is right for the patient and family based on their preconception and/or stereotype.

I think that we get into trouble as a team and as individuals in palliative care when we think we know the way a family should be acting. Or we think we know what's best for the patient and the family. That's where we lose our openness and our ability to be present, and we get into "this is the way it should be." Is it for their comfort or our comfort?

So I think that being open to the possibilities and not being rigid is one of the best things that we as palliative care people can be. And to really look at what are the patient's wishes, and to what are the family's wishes. And to ... trying to approach the situation from that standpoint. From looking to see where they are at, rather than where we are at, or what we think it should be. If we do that it makes things clear, it makes things easier. It feels like less of a fight sometimes.

We can't presume to know what's right for every family or patient. I know what's helpful in terms of symptom management. And I think I often know what's helpful in terms of trying to alleviate some fear. But in terms of exactly how it should happen, and what people should go through and what needs to be said, I think you really have to get to know the family to have a sense of that. It takes time, and it takes an appreciation of what their culture is... from an ethnic point of view and what their culture is from a family point of view.

Being open, flexible, and understanding appear to be key words describing her ideal care for the patient and family from other ethno-cultural groups. If the health care professionals are caught up with their own biases and prejudgements for their own comfort, they provide rather harmful and painful care for the patients and families. The will to understand the patient's viewpoint as well as the family's, and the effort to be aware of their own biases serve to clarify the seemingly complicated situations. This provides a better guide for the care. The bottom line is that each case is unique.

#### **4.3. issue two: verbal communication**

Without question, verbal communication is the most obvious and serious issue in any kind of area in health

care regarding the patient whose first language is not English.<sup>17</sup> In this section, this topic is addressed in two ways: how the language barrier causes problematic situations in PCU; and what kinds of issues the staff members have in using interpretation services.

#### 4.3.1. language barrier as problem

In the palliative care setting, the language barrier is considered problematic mainly in two ways. One is related to the symptom management and pain control which are the focus of medical care, and are monitored and approached twenty-four hours a day, seven days a week. In order to optimize the result of these, the communication between the care provider and receiver should be as clear and as precise as possible. Yet, unlike the more formal meeting where the interpreter is present, the health care providers frequently have to attend to and communicate with the patients regarding their symptoms and pain without a formal translator. “W” responded by talking about the communication sheet or translation chart in which simple expressions are written in English and the patient’s language: “That is why we are trying to develop these sheets for them. But, then you find sometimes that they can’t even read, right?” The whole situation seems to be very frustrating for the staff members. For instance, a Chinese female patient tried to report her pain to the staff members.

She would try and describe some of her pain as if she felt cold on the outside, hot on the inside. But, when the Cantonese social worker spent time with her she said, “It’s not really cold on the outside, hot on the inside at the same time. It’s that sometimes she feels hot on the inside, sometimes she feels cold on the outside and it alternates.” So that is a very different description on sort of fever and chills than something that’s happening simultaneously because that’s what it seemed like to the nurses who were trying to communicate with her. I mean it’s a very subtle thing but it’s an important thing, too. Because people were struggling. I mean who’s got goose bumps on the outside, hot on the inside and she associated it with pain as well. But, there are often very subtle differences. (“X”)

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<sup>17</sup>Some interview participants pointed out other important issues regarding verbal communication: I don’t know, I have found with certain cultures that even if they did speak English they are not going to open up emotionally to you anyways. You’re just not the right person to be doing that. So finding out what a person’s boundaries are all about as well, is another thing.. (“V”)

The ethnic view of ... whether people come from different cultural backgrounds, speak different languages, you can read a lot about what the norms are and what you mustn’t speak about. For example in the Chinese community it’s thought that you mustn’t ever mention death, certainly not to the person that’s dying. You protect them from that because you don’t want to tempt fate. So the families want you to speak to them and not to the patient. The thing is patients know. I think people that are dying are the first to know, and that always strikes me as, well not exactly amusing, that would be the wrong word perhaps, but that we can’t protect people from knowing that they’re dying. They’re the ones that know their bodies and feel the differences. *But there are other ways of talking about it without actually speaking.* (“X”)

“X” described another example,

She (another patient) kept doing something with her hands trying to describe something she had, and they thought she was having pain in her head when it turned out she wanted to have her hair washed. So her daughter said, “She wanted to have her hair washed.” And for days they thought she had pain in her head because she scratches her head or she does something to the top of her head and they were giving her more pain medication, it must be extraordinarily frustrating.

These kinds of miscommunication could end up with over/undermedication for the pain and mismanagement of symptoms, for instance. To make matters worse, these tragic results could be easily overlooked. The patients often have few means to complain about this mistreatment or become unconscious and die before expressing it. “X” put herself in the shoes of these patients,

There was this older woman and her family wasn’t always there, she had been in Canada for many years but she really didn’t speak hardly any English. So it’s like being trapped in your body where you can’t tell anybody what’s going on, it’s horrific really. I think of myself if I were in Hong Kong or some little village in China, how difficult that would be and frustrating.

The consequence of miscommunication in the palliative care setting could be “deadly” serious.

The other context where the language barrier becomes problematic is the discussion of the essential topic of palliative care. “Y” explained how difficult it is to communicate the issue of living and dying with the patient from other ethno-cultural groups respectfully and empathically.

It’s much harder to have the kinds of discussions about living and dying and what are your last wishes when you can’t speak the language and know the nuances of how to put things in more of a caring way. But we need to try hard to do that. We need to try and use words that work, that are understood, that are most compassionate and in an approach that’s respectful of where they are coming from as a family and as a particular ethnic background.

This suggests that it is almost impossible to provide social, psychological and spiritual care with language without help from an interpreter. This is a serious threat to PCU’s efforts to provide good care for everyone.

#### **4.3.2. issues surrounding interpretation**

The interpretation service has become available through the health care system for the last few years. “Z” appreciated this improvement: “We’re really fortunate now we do have interpreter readily available .... It used to be a real fuss to get an actual interpreter.” Yet, this is not enough according to “Y”.

Language is a big thing and I think that’s something we haven’t in Vancouver addressed very well. I feel strongly that if we are welcoming and bringing immigrants into the country and if some cultures in great numbers, we need to be able to provide interpreters and help with that especially in a hospital setting. I don’t think we do that nearly well enough. It shouldn’t be up to the family to do all the interpreting. It’s not right to put family members in that position, especially when the patients are so ill, you often have to

converse about dying. It's not fair to put a family member into that position. That often happens because of timing or lack of an interpreter in the hospital. I don't think that we do that well enough. That should be part of essential care. Especially for the populations that are quite large. I can understand we had a patient from a small country "A", you don't see that many here, fair enough that's an exception. For lots of the ethnic backgrounds that are here in great numbers we should be providing that.

Her argument was that the quantity of the interpretation service should be enlarged in terms of human resources and budget. Otherwise, the staff members rely on the family members for translation. However, the family should not be in the position to be the interpreter. This is because the family is a part of the patient, i.e., care-receiver, and the interpreter is a part of the care-provider. In other words, the family is to be cared for, not to care for, and the interpreter is to care for, not to be cared for in this context.

While the quantity of the interpretation service needs to be improved, its quality is also addressed. While the quality of the translation is usually unknown and unmeasurable to the health care providers, "X" described how to guess whether an interpreter is doing an appropriate job or not: "I might ask a question that's seven words long, for example, and then the interpreter speaks for two and a half minutes, and you know that that can't possibly be what I said. So, you have no idea what that other person is hearing." She questioned the quality of the interpretation service based on this kind of guess and expanded this questioning further. She had come to doubt the meaning of the interpretation itself as well as the presence of the interpreter, particularly, in the context of the deep conversation between a staff member and a patient:

To have a conversation of some depth with someone around ... feelings or what's important to them ... is very different when another person is interpreting for you .... Because it's not an intimate sharing between two people, because there's a third person there, so it makes it much more problematic.

This delineates a serious dilemma. The more an interpreter is involved in order to improve the quality of interpreting, the less profound the connection between a staff member and a patient becomes. On the other hand, the more the staff member and patient try to have an intimate relationship, the less the interpreter is involved, and the lower the quality of the interpretation becomes. This is another serious obstacle for PCU to achieving its goal, i.e., comprehensive care for everyone.

#### **4.4. issue three: communication and interaction without or beyond language**

Communication and interaction between health care professional, patient and family are much deeper than language in the palliative care setting, as well-illustrated in "W"'s episode.

We have had quite a run of young Chinese women dying. And my gut can tell me when someone is in anguish. Like K is in anguish and I had a weekend with her two months where you could feel her anguish, you could feel her sadness. It took us two months to get her some emotional support because it was negated what I was saying. And that is what is frustrating to me. Because I care to come in and she was sobbing and I asked her sister-in-law what she was saying and she said, "She's telling them even when she goes to heaven she will be watching them." And the pain and the anguish in this woman, you could feel it. I charted all this and I wrote it down to the best of my ability but another staff member said she didn't see it, somebody else said she didn't see it. It takes 6 weeks to 2 months before they can get someone who speaks her dialect who will listen and talk with her. So that is frustrating. She and I don't need to speak. She strokes my hand, I cuddle her, I kiss her cheek. I go as far as she will allow me to.

The non-verbal communication and interaction with the patient and/or family who speak(s) limited or no English seem to play a more significant role than they do with the English-speaking patients. "V" also addressed this issue in another instance.

We have a woman on the ward who is Cantonese-speaking and a lot of the staff are finding it frustrating in trying to communicate with her. I think that's sort of individual, because I rarely find it frustrating to communicate with somebody that I can't verbally communicate with. If I work with a patient for more than two days, we end up having a body language that we can read in each other, something I can always follow. So I haven't necessarily found it frustrating, but I know that there are other staff members that do find language to be a barrier to care.

...  
I think it's just a gift from life, from being intuitive, and in that sense knowing whether a person wants to be touched or hugged, or whether a person is not that kind of person, and they don't want to be touched or hugged .... Sometimes a hug is more powerful than talking. Sometimes a person just wants a shoulder to cry on. In that sense, it is a gift that I am intuitive enough just to know that, and that's why language is not such a frustration for me.

Furthermore, the non-verbal communication and interaction become more important than the verbal ones, in particular with the patient and/or family whose English is limited. "X" explained this:

I think words sometimes get in the way. That's what I think when I was talking about Mrs. T. earlier. Spending time with her, walking with her, smiling with her is a need for them just even sometimes if it's a nod. In a way, it's sort of bowing to people that seems to work in a number of cultures .... My way of showing that I care about someone or to communicate without words is to embrace a person. It's very North American, of course, it's part of Europe too, but I'm very conscious, too, that's not appropriate for many people. Sometimes it comes out of my own need and if I want to embrace them and they come from a different culture I will ask.

In summary, the non-verbal communication and interaction have to play a more vital and critical role in the environment where the verbal ones are hardly established. Therefore, the question for this section is as follows:

What kinds of strategies, ways or modes do the staff members employ to communicate and interact non-verbally with the patients from other language groups when they are dying? This question is addressed in terms of being, listening, touching, and music.

#### 4.4.1. being: a human being rather than a human doing

All of the interview participants happened to use one word to delineate the core of palliative care. That is “being.” “X” stressed, for instance, “the biggest task that people have to learn is to be a human being rather than a human doing.<sup>18</sup>” Here, the word “being” is used in two ways: “being” with and the “being,” or presence.

Being with the patient is extremely important for the staff members. “Z” emphasized that being with the patient in the moment seems much deeper than people can imagine.

It’s so important in that setting most particularly to be with the person in that moment because that’s all that matters. And even that concept was new to me and every time I heard it in various workshops or readings over the last six, seven or eight years, it has grown layers to it. It has gone to a different and deeper meaning to me. But, for a person who has a terminal illness, it’s really important to be with them just right then without judgment and without an agenda.

Just being with and not doing anything, according to “W”, is the essential component of the palliative care, not only from the staff’s point of view but also from the patient’s.

I did a little mini-survey and asked about a half a dozen patients, this is what I have to offer you, who I am, and what is it that you want from me as your caregiver? And everyone used one word. The one word that they all used was “be”, as in be with me. In all the different ways they said it, only to just sit with me or be with me. And when people are dying that is what they want more than anything.

Ideally, the interviewees would like to spend as much time as possible just being with patients. However, this hope causes the conflict with the limited resources and time in the reality. “X” depicted her frustration.

We don’t always have to be doing and often it’s the doing that we miss, but just to be able to sit down and take time with people. That’s the frustration, because the gift we have is giving of ourselves and our time. The thing we’re limited in, in healthcare today, is time and resources because palliative care is time intensive, as opposed to other parts of the health care profession that may be task intensive. Like you have to do a dressing or an assessment or these tasks that you might have to do as a social worker or a doctor or whatever. But, in palliative care, what the resource that is needed here is the resource of time, just being there.

No matter what her/his professional title is, it is hoped that the staff member is being with the patient, giving her/himself and time. Here, the job title appears to be connected with the task-intensive sphere of the health care.

Meanwhile, the being of the staff is more significant in this time-intensive environment of the palliative care.

The being or presence, of the staff members, patients, families and friends is much more profound than the

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<sup>18</sup>Regarding this, Kearney points out as follows:

In working with another in suffering the carer him- or herself is an essential part of the healing process ... the being (who we are and how we are with the patient) is primary and the doing (the actual practice of skilled and effective caring) follows. (Kearney 2000, 91)

doing of something.<sup>19</sup> “Y” delineated the being in practicing palliative care by clarifying how and when to be present.

When you are at work, there’s opportunity to be still and to be just present, maybe we’re not sitting and formally meditating, like you know. But you are being present and there are times when there’s nothing that you can do. It’s good not to do anything. Not to feel like you have to do anything and to be comfortable not doing anything and just being present. Often I find that’s the greatest learning and teaching, both. Because if you are able to just be present, often the family can pick up on that energy. Families are really anxious and scared and they have never seen anybody die. You enter the room, and your energy is very calm, and you are a little nervous about something that’s happening. But if you can just still yourself and be present, and not feel like you have to rush and do anything, the whole energy shifts and it really helps them to be more present. I just learned so much about that. Because when I first did my first locum, I was really nervous. How do you talk to families about dying and what do you do when people are dying? I have to be a palliative care doctor. What am I going to do? I soon learned that if you don’t know what to do, you just be quiet and still and it will come to you.

She continued discussing the being of the health care provider by defining the being as the universal sense of calmness and lack of fear.

I think that it is universal in the sense of feeling one’s energy, or accepting calmness. Different people will put different words to it. Different religions might call it different things. Some might call it meditation. Some might call it prayer. Whatever people call it, I think that there is something to be said about a presence and a lack of fear. I think that, in many different cultures, there are a lot of unknowns around dying, death and fear, not necessarily about after death. Because that is one of the things that religion can help with. It can provide a framework of what’s next. The dying process is more unknown. So I think that many cultures often share a fear of the process of dying, of the physical parts, the fear of pain and the unknown. So I think that your presence and your lack of fear of that process can be felt and appreciated and helpful to many different cultures. There are other differences and things that you need to know to help, serve your patients and their families better. But, in terms of that general feeling, I think that is universal. Your sense of presence and calmness in a room when someone is dying .... I do think that’s universal.

The presence, calmness, and lack of fear are the best medicine for the universal fear of the physical aspect of the dying process, mainly pain.

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<sup>19</sup>The being of a patient is significant. For instance, a patient from a long time ago made “Z” aware of the significance of the being: “She (the patient) had an immense, immense being ... I was aware of her dignity. So now, in retrospect, I have watched a being she was.” “Z” recalled the patient vividly,

I remember a lady that I had. That lady I specially well treated for strokes and she will forever remain in my mind as an epitome of dignity. She was a Cree lady. She had had a stroke so that she couldn’t speak and of course she only spoke Cree. But I can see her to this moment with her snow white hair braided. She always looked immaculate. Obviously the nurses helped her with that because she had quite a significant paralysis. But she would sit and I would be working on her with sitting balance and practice in getting from sitting to standing and she always had the greatest dignity in her person. It was just amazing. It almost takes my breath away. She was a remarkable woman. Again, she was a very long way away from home .... She was away from her family, her people, there were certainly other Cree individuals around the area, but .... Her vision of her sitting in the room working with me and just maintaining the greatest dignity, it always amazes me. I always think of her.

#### 4.4.2. listening

Everyone agreed that listening is another essential component of palliative care. The important thing is deep listening with care and presence, as “Y” stressed, not answering a question or solving a problem.

Everyone says that we have to communicate well, but they forget how helpful listening is. And if you are really and truly a deep listener and you really care, people feel that. And whether you can solve a problem or answer the very question, if they believe that you are listening and you really care and ... you are present ... they feel it. Then, it just makes so much difference to them whether you know the answer or not, whether their loved one’s going to die. That’s ultimately what’s going to happen ... you can’t stop or change that, but you can care about what they are feeling. You can try and answer the concerns they have. And again the more time you spend in communicating, listening effectively, the better that experience is going to be, and the more calm the family members are going to be.

Again, how the health care professional is being with the patient or family is the underlying theme for the listening.

How the listener is being is critical as well. Being with them in a most profound way as well as being in a most genuine way are the core of compassionate, caring and healing listening. “Y” illustrated this by using an example.

It was a Romanian couple and the husband is fit and young. His wife is dying very young and he was very worked up. He’s had a bad experience himself with the medical system. And he’s scientific and wants information and it frustrated and probably angry because his thirty-nine year old wife is dying. And the staff was saying he’s upset about da da da da .... He was and I went and took him aside. He talked to me for a good hour on Saturday. Most of the time I just listened to his ideas about hospital and medicine and how different it was from what things were like in Romania and his beliefs about healing and spirit. It was actually very fascinating. We had a wonderful conversation. Mostly, I just let him talk. I couldn’t solve his problem that his wife was dying. I could address some of the concerns he had. I could say, “Yeah, that’s terrible that that happened. It wasn’t right that that happened.” I didn’t solve his problems but ever since that conversation everyone said he’s so much calmer. And I didn’t change the inevitable and I didn’t take away his anger cause he’s still angry. But I just listened and he’s calmer and it made a difference. It took an hour, which seemed like a long time, but it’s not because of his whole being after that. He can be more present for his wife and all the other staff is calmer too. So it pays off, just listening and again being willing to take the time ... it doesn’t take a lot.

The listening with compassion and empathy means more to the patient and/or family from other ethno-cultural groups who speak/s limited English. As described in this instance, the patient and/or family from other ethno-cultural groups is seriously suffering from the major differences in health care and is frustrated with the communication problem. When the staff members listen to the patient or family deeply, no matter how awkward her/his English is, accept compassionately, no matter how frustrated s/he is, and are “being with” profoundly, no matter who s/he is, the language barrier and cultural difference seldom mean anything to them.

#### 4.4.3. touching

Touching also symbolizes the core of what the caregivers do in the palliative care context. Among the

interviewees, touching is considered not merely in the physical dimension, but in a more holistic way. Touching means physical as well as spiritual connections between people, including the staff members, patients, families and friends. Touching is another manifestation of being with profoundly. Touching seems to be a more obvious and powerful form because of its physical aspect. For example, “Z” recalled the connection she had with a non-English speaking patient.

If I did have any interaction with her with the understanding that she’d like to have a massage or touch, you know, when you saw me go to see her, she usually relaxed a little bit. I felt she was welcoming what I [inaudible on tape] in her and we had a connection together because we had worked together on a very physical level as well so [inaudible on tape]. Smoothing...soothing spiritual kind of connection.

Meanwhile, touching is considered a more effective and efficient way of communicating without language. “W” explained this in an example: “she (a patient who could speak limited English) and I just communicate by touch more than anything.” She continued: “I just sat with her on night shift, and just sat beside her and held her hand, or just sat beside her. And she knows that I am there. And she’ll wake up and she’ll touch my cheek and you know, things like that, so she knows I am there and she says she is frustrated that she can’t tell us what she is feeling.” Touching is a direct approach to emotional and spiritual pain. “X” also commented on this point.

She [a patient] was in a lot of what appeared to be emotional and spiritual pain. We were able to have conversations through the interpreter not to any depth. I think the way I could best communicate with her would be by touch. But then you have to be careful if that’s appropriate for her. But at some level, it seemed to be so, and ... ,um, ... we would just smile, and ... ,um, ... showing that you cared about her.

The interview participants were well aware of the differences in views towards physical touching. Yet, they were also aware of the gap between the stereo-typical difference toward touching among cultural groups frequently found in the literature, and the actual difference among the individuals from various ethno-cultural backgrounds in the field. For instance, “W” stated, “it is touch and you can see some cultures are not open to touching, but I found very few that are not open to a touch.” In their opinion, based on their first hand experience, thus, touching is a more universal means to communicating and interacting without language than the literature suggests.

Touching has more symbolic meanings for them than discussed above. Touching gives significantly profound, holistic and humane meanings for the interviewees. “X” described how meaningful working in PCU is: “So often you are touching people’s lives so it’s really important. That’s where the meaning comes from.” Meanwhile, “U” summed up that all she does in the palliative care setting is “touching souls.”

#### 4.4.4. music

Music plays a significant role in communication and interaction without language. According to “U”, music is a tool “to communicate with patients and a direct means of communication.” She continued, “In music you can do all those things we do with words but you can do it in a non-threatening way and I think ultimately for many, many people much more effectively.” The core of the interaction and communication, i.e. being with, is also addressed: “music is a wonderful way to be with people. It’s a very easy way to be with people, ... it’s not difficult for them to be, whereas it might be with words or in some other way.” She also claimed that music unites people: “I have seen in a facilitated time people come together through music. They can’t speak to each other but they can sing, or just be together in music with that person who’s dying, and that’s just tremendous healing. A model of a way of being together, when words tear people apart music can bring them together.” Considering these characteristics of music, she considered “music as a healing phenomenon.” These views were well implied in an example provided by her:

We had a woman years ago ... she had gone blind as a result of the cancer, and she was Cantonese-speaking. She didn’t speak English, her son spoke English, he was her voice. She didn’t have a voice on the unit and she had lost her sight, she was terrified, so fearful, crying but relatively still functioning physically. One day, the physiotherapist was walking her down to our lounge, and I was playing the piano at that time. I invited her through gestures to come and sit beside me, which she did, and directed her hand to the black keys, which is a pentatonic scale which would be a fairly new sound to her. We started to play together and it was just the most stunning moment, it was one of those moments where everything stopped, the whole unit actually stopped. People knew this person as fearful and crying out, we had no real idea of her as a person, because she wasn’t able to share that with us in any meaningful way. That’s the wonderful thing about this music is that you don’t need for specific types of prepared situation, like the black keys on a piano, you don’t need prior musical skills in order to be able to express your emotions. So what we heard from her was gentle and sweet and kind and full of sunshine, and she started to smile and it just allowed her to draw this curtain back from her personality she hadn’t been able to show us in any other way. People literally stopped, and they couldn’t believe what they were hearing, coming from this person who was so fearful. That was lovely and a wonderful *entre* into other times when she would come and sit and improvise regularly. It was a really lovely time to share because you communicate so immediately in music and no one could deny that we weren’t speaking to one another. You just couldn’t say that wasn’t happening. She was listening and responding, and exploring and expressing herself. It was really very beautiful.

Yet, music is not always appropriate for everyone in the context of palliative care. Some patients and families “are just not as accepting of music.” “U” continued as follows: “So I do find that a lot of the Cantonese-speaking families that have come in, I don’t get the same *entre* to them as I do with other families. I’m not entirely sure if that’s a cultural thing. I think part of it is individual response to that person’s distress, and the types of families that we have had come in.” Even though these families do not accept music in the first place, she emphasized, there are times for them to welcome music.

I do find with families and this is true of all families, regardless of cultural differences, if people are resistant to music initially, they tend to be much more open to it once that person is non-verbal, and is in that transition place between life and death. People tend to at that moment, because they see the person they love so altered, to perhaps be open to something that is also different. Often times we get asked to come and play in situations where it hasn't been possible before. And there are very powerful moments that happen when you support people, and there's a tremendous wave unifying a group of people.

## 5. Discussion

On the surface, the interview data seem to simply represent the struggles and challenges that the health care professionals experienced in providing hospice palliative care to the people from different ethno-cultural backgrounds. However, the distinction between the ongoing care and the intimacy of dying helps to detect a different layer of the phenomenon which is hidden by these obvious struggles and challenges. This more profound and deeper layer is delineated through the concept of *communitas* or *antistructure* mainly in two ways: (1) the interviewees are forced to reconsider the common, regular and normal concepts in Western health care and to question some of them due to the cross-cultural encounter with the patients and families in the death and dying process, one of the most serious situations in life; and (2) they often connect, interact, and communicate with the patients and families in the "I and thou" mode without or beyond verbal communication.

First, the "common sense" of the Western health care is uprooted for reexamination, reconsideration, and questioning.<sup>20</sup> This is already evident in the hospice palliative care context in general where the emphasis is on care rather than cure. Yet, it is more obvious in practising hospice palliative care for ethno-cultural others. For example, the Western concepts of family and individual are reconsidered in terms of (1) patient and/or individual autonomy and rights, (2) decision-making process, power relation and communication in family, and (3) death education for children. These concepts belong to the core of the Western medical health care ethics. In particular, patient autonomy, patient rights, informed consent, truth-telling and decision making are reexamined and under critique. This situation has caused confusion among staff members because these concepts are fundamental elements to the practice of hospice palliative care in the modern tertiary care hospital in the North America and, furthermore, there is

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<sup>20</sup>Turner explains that these kinds of experiences of stripping off and levelling in *communitas* or *antistructure* provide opportunities for "those who have taken their culture for granted to rethink what they have hitherto taken to be its axioms and 'givens'" (Turner 1974, 256). In this situation, Burridge claims, "[t]he boundaries of given cultural categories are transcended, fresh rationalizations and new moralities may emerge (Burridge 1979, 157)."

not any clear framework, guideline, or grid to deal with the situation.

Another instance is that the stereotypical definition and description of the ethno-cultural group frequently found in literature are stripped off and levelled. The staff members' experiences of intimate and close encounters with patients from different cultures help them to see them as living, unique individuals, not as oversimplified and caricatured strangers. The professional care providers have come to realize that there is unlimited individual variety in an ethno-cultural group at the same time as the commonality and universality of human beings across cultures exist. In sum, the experience of *communitas* or *antistructure* forces the staff members to deconstruct the stereotypical view toward ethno-cultural others constructed in the Western health care context, and to have a more flexible and open attitude.

Secondly, non-verbal communication and interaction, such as being with, being/presence, calmness, and lack of fear, listening, touching, and music, are frequently used to establish profound connection as in the "I-Thou" relationship. In other words, these channels of connection are characterized as *antistructural* or *communitas* and penetrate the patient-physician boundary which is constructed in the Western health care context. Indeed, this is true for all the patients in the hospice palliative care context, in particular the patients who can no longer communicate verbally, or who are not conscious (Albom 1997; Boulay 1984; Byock 1997; Callanan and Kelley 1992; Hennezel 1997; Kearney 1996, 2000; Kuhl 1999; Levine and Levine 1982). This tendency is more distinct in the context of providing hospice palliative care for the patients from other ethno-cultural groups. This result may indicate that shared cultural ground, such as language, cultural norms and practice, beliefs, and religions, seems to contribute to having more surface communication, interaction and connection and to become an obstacle for another form of encounter, raw, human, profound and deep. Buber supports this point as follows: "Every means is an obstacle. Only where all means have disintegrated encounters occur (Buber 1970, 63)." Conversely, "Before the immediacy of the relationship everything mediate becomes negligible (Buber 1970, 63)."

The context where these sorts of non-verbal communication and interaction occur is further explained by

Buber in terms of “the present,<sup>21</sup>” “love,<sup>22</sup>” and “spirit<sup>23</sup>” besides “I-Thou” relationship. This holistic, genuine, and profound time and space, according to the interviews, are often experienced by the health care professionals in providing hospice palliative care for the patients from the other cultural backgrounds. This kind of moment impresses the staff members significantly. This is not only because they have this sort of experience with the patients from other cultural groups more often than the rest of the patients, but also because they have this kind of connection with them more frequently than surface interaction, such as verbal communication, which is difficult to establish.

This kind of experience of *communitas* or *antistructure* is too raw and profound, occasionally overwhelming for the people in the institutional structure. Sometimes it could be eye-opening and groundbreaking, but other times it could be dangerous and destructive. Thus, the importance of “structure” against “*communitas* or *antistructure*”, “I and It” against “I and Thou” relationship, “*persona*” against “individual”, and “work *persona*” against “inner healer”, needs to be emphasized (Buber 1970; Burrige 1979; Kearney 2000; Turner 1969, 1974).

## 6. Conclusion

This thesis is a qualitative research investigating the experiences of the health care professionals who provide hospice palliative care for the patients, families, and friends from other ethno-cultural groups. The research data were presented under the common themes, (1) staff’s perspectives on culture, (2) family issues, (3) verbal communication, and (4) communication and interaction without or beyond language. Then, the analysis has revealed the centrality of “*communitas* or *antistructure*,” “I and Thou,” “individual” and “inner healer” in relation to “structure,” “I and It,” “person” and “work *persona*” in the context of hospice palliative care. In particular, this tendency is more evident in the interviewees’ experiences of providing care for the patients from other ethno-cultural

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<sup>21</sup>The present - not that which is like a point and merely designates whatever our thoughts may posit as the end of “elapsed” time, the fiction of the fixed lapse, but the actual and fulfilled present - exists only insofar as presentness, encounter, and relation exist. (Buber 1970, 63)

<sup>22</sup> Man dwells in his love .... [I]t is between I and You (Buber 1970, 66).

<sup>23</sup>Spirit is not in the I but between I and You. It is not like the blood that circulates in you but like the air in which you breathe. Man lives in the spirit when he is able to respond to his You. He is able to do that when he enters into this relation with his whole being. (Buber 1970, 89)

backgrounds. Here, the basics, norms and common sense of Western health care are frequently reconsidered, reexamined, and questioned. The non-verbal communication and interaction often enforce the health care professionals to experience raw and profound connection with the patients and to outmatch the verbal ones. Yet, the appropriate balance between antistructure and structure, "I and Thou" and "I and It," "individual" and "person," and "inner healer" and "work persona" needs to be established according to each individual situation. In particular, the proper verbal communication and ethical grid should be accomplished. Mutual understanding and respect comprise the goal to achieve.

This is an interpretative study. The data gathered does not necessarily reflect the views of all the staff members of the unit. The interviewees who voluntarily participated in the research hardly had negative views of or experiences in caring for the patients from other ethno-cultural groups. Hence, the rest of the staff might have some negative perspectives on the patients from other ethno-cultural backgrounds. Another restriction of this study is that the ability of the interviewer to conduct English in these interviews is limited due to the fact he has been speaking English only for a few years. Future research should investigate the experiences of the patients, families, and friends from other ethno-cultural groups in receiving hospice palliative care. In this way, a more total, holistic representation of the reality in this context is delineated. In addition, the number of interviewees should be increased in order to gather less biased data and produce more generalized results.

The core and essence of hospice palliative care was developed by Saunders from the experiences of *communitas* or antistructure, "I and Thou", "individual", and "inner healer" in providing care for the dying patients from other ethno-cultural groups. The consensus is that hospice palliative care was born from the Christian tradition. However, the biography of Saunders, the founder of hospice palliative care, clearly illustrates that she gained its essential idea and philosophy from her experiences caring for two patients from another ethno-cultural group. After she had obtained this core and essence, she needed to elaborate them with the systematic medical, psychological, and social care to actualize her dream, i.e. hospice palliative care. (Boulay 1984) This study may have suggested that the core and essence of hospice palliative care sprung from the raw and profound experiences of *communitas* or antistructure, between different cultures, and between life and death, where people often connect with each other naked, bold, and straight, and where they frequently meet on "human" or existential levels regardless of culture,

language, religion, or skin color.

The first patient of Cicely Saunders, the founder of hospice palliative care, was David Tasma, a lonely, uneducated, lower-class, Polish Jewish immigrant. Saunders encountered Tasma, a living symbol of *communitas* or *antistructure*, in his dying process characterized by *communitas* or *antistructure*. This profound experience has inspired her to create hospice palliative care. In particular, his words, “‘I only want what is in your mind and in your heart’ (Boulay1984, 172),” still live in the core of hospice palliative care, long after this Polish Jewish immigrant died alone in England. Hence, having promised to her before he died, “‘I’ll be a window in your home’ (Boulay1984, 58),” he seems to have become a window for hospice palliative care.

Earth fills her lap with pleasures of her own;  
Yearnings she hath in her own natural kind;  
And, even with something of a mother’s mind,  
And no unworthy aim,  
The homely nurse doth all she can  
To make her foster-child, her inmate Man,  
Forget the glories he hath known,  
And that imperial palace whence he came.

*Ode: Intimations of Immortality from Recollections of Early Childhood* by William Wordsworth

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**Appendix A**  
**Letter of Invitation**

**Appendix B**  
**Consent Form**

will have no impact on your position or employment. If you experience emotional distress as a result of the study, counselling services will be provided through the Counselling Psychology program at UBC. Prof. Marv Westwood will serve as the contact for counselling. You may obtain a copy of your own interview transcription and a copy of the thesis. We are unable to pay you for your participation.

If you have any questions about this study please feel free to contact Prof. Bill McKellin, Dept. of Anthropology and Sociology - 822-2756. The phone number for Prof. Marv Westwood, Dept. of Counselling Psychology is 822-6457. If you have any questions regarding your rights or treatment in a research study at the University of British Columbia you may contact Dr. Richard Spratley, Director of the Office of Research Services at 822-8598 or Dr. Jim Kennedy, Chair, UBC/Providence Research Ethics Board at 806-8164.

**Consent**

I understand the information provided about my participation in this interview and have had all of my questions answered to my satisfaction. I understand that I may ask questions at any time about this interview and that I may withdraw my participation. I have a copy of this letter and consent form for my records.

I consent to participate.

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Name of Subject

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Signature of Subject                      Date

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Signature of Witness                      Date