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*Maj-Helen Nyback*

*Generic and  
Professional Caring  
in a Chinese Setting*

*An Ethnographic Study*

馬到成功



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# GENERIC AND PROFESSIONAL CARING IN A CHINESE SETTING



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Maj-Helen Nyback

ÅBO 2007

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## **Abstract**

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**Åbo Akademi University, Department of Caring Science, Finland**

**Supervisors:** Professor Katie Eriksson and Professor Terese Bondas

The objective of the present study is to describe the cultural care practices, meanings, values and beliefs which form the basis of caring in a Chinese context. The research has its starting point in a caring science perspective and a qualitative research approach with interpretative ethnography as methodological guideline. The theoretical perspective is formed by elements of the theory of caritative caring, developed by Eriksson, and the theory of Culture Care Diversity and Universality, developed by Leininger. Previous research of suffering, culture and caring is described and also a presentation of actual transcultural nursing research as well as a presentation of the social structure dimensions of Chinese culture is included in the theoretical background. The empirical part includes patients and relatives, nurses and Hu Gongs as informants. The data collected are analysed based on Geertz's idea of forming "thick descriptions" through examining the "what, how and why" of people's actions.

The findings show that the family has a prominent position in Chinese caring practices. The patient plays an unobtrusive role and a mutual dependence between the patient and the family members is evident. The professional nursing care is an extended act which includes the family in the caring relationship. The care practices of the Chinese nurse are characterized by great professional nursing skills. Suffering is described by the informants as being caused by disease, pain and social circumstances. "Social suffering" is described as worse than physical or mental suffering. Culturally competent and congruent care is a prerequisite for avoiding cultural pain, imposition and blindness when caring for the suffering human being.

The findings of the present study necessitate a broadening in caring theory to include the family in the caring relationship. A further conclusion is that a broadening in our perception and understanding of culture would promote the delivery of culturally competent and congruent care. Suffering need to be seen as enclosed in cultural patterns of how it is expressed, interpreted, understood and relieved. Care and caring need to be seen as embedded in culture and the care practices values and beliefs have to be congruent with the cultural patterns where the care is provided.

**Key words:** suffering, cultural care, generic care, professional care, China



*To my family*

## Acknowledgements

Culture and its influence on people's lives has always been a source of curiosity to me, and this brought me to China and to an ethnographic research in which my interests, Caring Science and culture could meet. The present dissertation is the result of ten years of reflection and pursuit of knowledge and insight in Chinese cultural caring practices, meanings, values and beliefs. The insights gained are then combined with Western Caring theories, and the path to the final conclusions have not been straight forward, merely it can be described as an explorative journey.

The research has been a journey in many ways. It has been a geographical journey, involving travelling to China, and a cognitive journey in which the search for knowledge has forced me to create new patterns of interpretation and understanding. This would not have been possible without guidance. I firstly want to cordially thank my supervisors, who have followed me on my journey – Professor Katie Eriksson who inspired me and never lost faith in my ability to complete this journey and Professor Terese Bondas who has had a big influence on the development of my critical thinking and in becoming a researcher. Besides your professional support, your friendship, patience and interest gave me strength to finish this project.

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Björköby 06.12. 2007

*Maj-Helen Nybäck*

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# INTRODUCTION

## 1. The rationale of the study

As a result of the world-wide movement of patients and caregivers in today's society, there is a need for further knowledge about cultural patterns in the experience and expression of suffering and expectations of care and caring. It is an unquestionable fact that we, when caring for each other, need willingness and also a desire to learn about each other and to gain cultural knowledge and skills, in order to avoid inhuman acts like racism, ethnocentrism, cultural blindness and cultural imposition in caring. The values that undergird caring exclude any acts that destroy life, violate dignity and increase suffering. However, these acts can unfortunately be carried out simply due to the care recipient's limited cultural knowledge.

Over a period of several years I have been responsible for student exchange between Svenska Yrkehögskolan, University of Applied Sciences in Finland and Fujian Medical University and Fujian University of Traditional Chinese Medicine in China. I have had the opportunity to act as guest teacher at both these Chinese Universities several times during a period stretching from 1997 to 2005. This provided a unique possibility to learn to know Chinese culture care practices and an interest arose to conduct a study regarding suffering and generic and professional care practices, meanings, values and beliefs in a Chinese setting. The present study is an ethnographic study focusing on patients', relatives' and nurses' experience, expression, interpretation and alleviation of suffering as well as the "generic" and "professional" care in one Chinese context represented by three hospitals in Fujian Province in People's Republic of China. The term generic care applies to the lay, traditional, emic care knowledge and practices (Leininger 2005a), whereas professional care means the specialized care knowledge or skills for which professionals are either paid or agree to volunteer (Haigler, Baure & Travis, 2004).

The majority of research concerning suffering, care and caring used in the present study has been published in the Western world. This creates a tension in the study and shapes patterns of interpretations which carry both Eastern and Western cultural values. Care and caring are embedded in culture, and culture is shaped by the human being's practices, meanings, values and beliefs (Leininger, 2005a). Suffering is universal and it affects all people regardless of birth place, culture or station in life. The human response to suffering (physical) and need for care are similar throughout the world, but the actual need for

care and the expressions of it vary depending on cultural identity. In this study, patterns of interpretation, which are related to each other and create an understanding for how suffering and caring is experienced, expressed, interpreted and understood among patients, relatives and nurses in a Chinese context, will be described.

## **Specific features of the study**

The present study has both a theoretical part and an empirical part. The specific features of the study are outlined below as well as a description of the composition of the presentation of the study. The introduction aims at structuring the study and consequently the aim and research questions are presented in the first chapter.

The research process of this study began with gaining understanding for the field of study by getting acquainted with the culture in question. This formed an “etic understanding”<sup>1</sup> representing the outsiders view. This is seen in the description of the aspects of Chinese culture which forms a part of the theoretical background. Understanding the field of study also requires getting acquainted with the different topics (how suffering, caring and Chinese culture are described through earlier research) and developing a theoretical perspective. A tension occurs between a possible pre-understanding gained through literature written in Western culture, and knowledge gained through an empirical study conducted in one Chinese cultural context. The tension created is between what is expected, based on pre-understanding, and the reality of the unexpected unknown world of a new culture. The pre-understanding can obscure the seeing, but it can also form the basis of a new understanding. A description of the concepts “culture” and “transcultural nursing” with related research fields, are added to the first part of the study. Transcultural nursing is relatively new in Finland and it is important to enlighten this research area and to introduce different research traditions in order to develop cultural understanding. This forms the background of the study and is found in chapter 2–5.

In chapters 6–9 the methods used for the empirical study are outlined. This study is inspired by interpretative ethnography as it is described by Geertz (2002a, 2002b, 2002c)<sup>2</sup> who states that to understand the culture you have to

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<sup>1</sup> The “emic” perspective refers to the insider’s view while the “etic” perspective refers to the outsider’s interpretation of the culture (Leininger, 1991, 2002a, 2005b).

<sup>2</sup> Geertz’s “The interpretation of cultures” was published in 1973 and a new edition was published 2000 (in this study referred to as Geertz 2000a). Geertz’s “Local knowledge. Further essays in Interpretive Anthropology” is published in 1983 and reprinted 2000 with a preface to the 2000 edition (here referred to as Geertz 2000b) and Geertz’s “Available Light. Anthropological Reflections on Philosophical Topics” is a collection of previous published essays (1983 – 1999) (here referred to as Geertz 2000c).

grasp the meaning of the actions in the culture. A description of behaviour is merely a “thin description”, but a description of “who people think they are, what they think they are doing, and to what end they think they are doing it” is a “thick description”; “*a stratified hierarchy of meaningful structures*” (Geertz, 2000a, 7). In this study emphasis is put on “thick descriptions” of practices, meanings, beliefs and values of the acquired information.

In caring science, “thick descriptions” of a culture are needed. Caring science needs answers to the questions “what?”, “how?” and “why?”, when searching for substantial knowledge in caring for the suffering human being, and when searching for culture care meanings and values. The beliefs that underpin values in a given culture can be seen as “thick descriptions”, describing why care practices operate the way they do. Geertz (2000a) continues by claiming that once human behaviour is seen as a series of symbolic actions, the question concerning whether culture is a patterned construct of a frame of mind, or whether they are somehow mixed together, stops making sense, since the main focus should be on how these are important. Ethical considerations are highly relevant in an ethnographic study therefore ethical standpoints are discussed from various angles.

The findings are presented in chapter 10. In this study “thick descriptions” consists of what happens in a ward at a hospital. The thick descriptions are practices and meanings that patients, relatives and nurses see in the daily life at the hospital, as well as the values that underpin these practices and the beliefs that direct this life. These practices, meanings, values and beliefs form meaningful structures which describe the culture. This can be seen, for example, in the patient’s personal preferences and feelings concerning having relatives present in the ward; the significance of their presence related to the patient’s suffering and their possibilities in alleviation of the patient’s suffering. Matters such as how the relatives are meeting the patient’s need for care and how they through generic care<sup>3</sup> can alleviate suffering, as well the nurses’ interpretation of the situation and how their professional care creates alleviation of the patient’s suffering display these structures. All the practices have a meaning and the “thick descriptions” are formed by viewing the practices and meanings related to suffering from different angles, discovering the values that underpin the alleviation of suffering and the beliefs directing actions to alleviate suffering. Together these factors form patterns of interpretations of the experience, ex-

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<sup>3</sup>Leininger (2005a, 14) describes generic care as “*the learned and transmitted lay, indigenous, traditional or local folk (emic) knowledge and practices to provide assistive, supportive, enabling and facilitative acts for or towards others with evident or anticipated health needs in order to improve wellbeing or to help with dying or other human conditions*”.

pression, and understanding of suffering and caring among patients, relatives and nurses in a cultural context.

The study ends with conclusions based on the theoretical perspective and the empirical findings, and a critical evaluation of the research process. Suggestions for continuity in ethnographical research are discussed. These can be found in the section named “discussion” in chapter 11 and 12.

## **Aim, research questions and design of the study**

The primary objective of the study is to depict the cultural patterns of how suffering is experienced and expressed among patients and relatives and how generic care is delivered in care practices, meanings, values and beliefs in a Chinese hospital setting in Fujian Province, People’s Republic of China. The second aim concerns the nurses and the cultural patterns seen in professional care; the nurses’ practices, meanings, values and beliefs that affect the care of the suffering patient in a Chinese hospital setting in Fujian province, Peoples’ Republic of China. The influence of the social structure is discussed with the purpose of gaining a deeper understanding of cultural practices, meanings, values and beliefs.

The construct of culture care is used in the research questions and according to Leininger (1991, 2002b, 2005a), who coined the concept it combines culture and care by describing the specific features that can be seen in a culture in the area of care and caring. A construct has many ideas embedded in it, whereas a concept has a single idea. The motive for using culture care as a construct in this study is that care and caring are embedded in a given culture and are essential parts of that culture. The focus is not only on culture or only on care, but on how culture influences care and caring through the practices, meanings, values and beliefs, deeply rooted in the culture under examination. The research questions which direct the study are;

1. What are the culture care practices, meanings, values and beliefs concerning generic caring and suffering among patients and their relatives in a Chinese hospital setting?
2. What are the culture care practices, meanings, values and beliefs among nurses, which influence professional care practices aiming at alleviation of suffering in a Chinese hospital setting?

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3. How does the social structure (represented by economy, religion, health care, education, family and the values underpinning the development of cultural expressions) influence the experience and expression of suffering and the alleviation of suffering through caring in a Chinese context?

The overall methodological approach of the research is interpretative ethnography, inspired by Geertz (2000a, 2000b, 2000c). The study will describe and give interpretations of some of the practices, meanings, values and beliefs of patients, relatives and nurses, from the insiders' or native's point of view (emic perspective). Geertz (2000a) states that every cultural analysis originates in a pre-understanding gained through literature review and familiarization with the culture. Studies that are based on other studies do not continue where the others have left off, but can instead plunge more deeply into the subject with greater knowledge and clearer concepts. Previously discovered facts and concepts are used to penetrate further into the area of the study.

The pre-understanding is of vital interest since it will help the researcher to see and understand (but might also obscure the "seeing"). Consequently the understanding of what is seen is based on a pre-understanding of as well as a certain perspective on the study. The pre-understanding is developed in the theoretical perspective and the theoretical background of the study. The study has a theoretical part and an empirical part, which belong together. The design of the study is visualized in Figure 1.

What are the patients', relatives' and nurses' experience, expression, interpretation and alleviation of suffering and which are the "generic" and "professional" care practices, meanings, values and beliefs in a specific Chinese context.

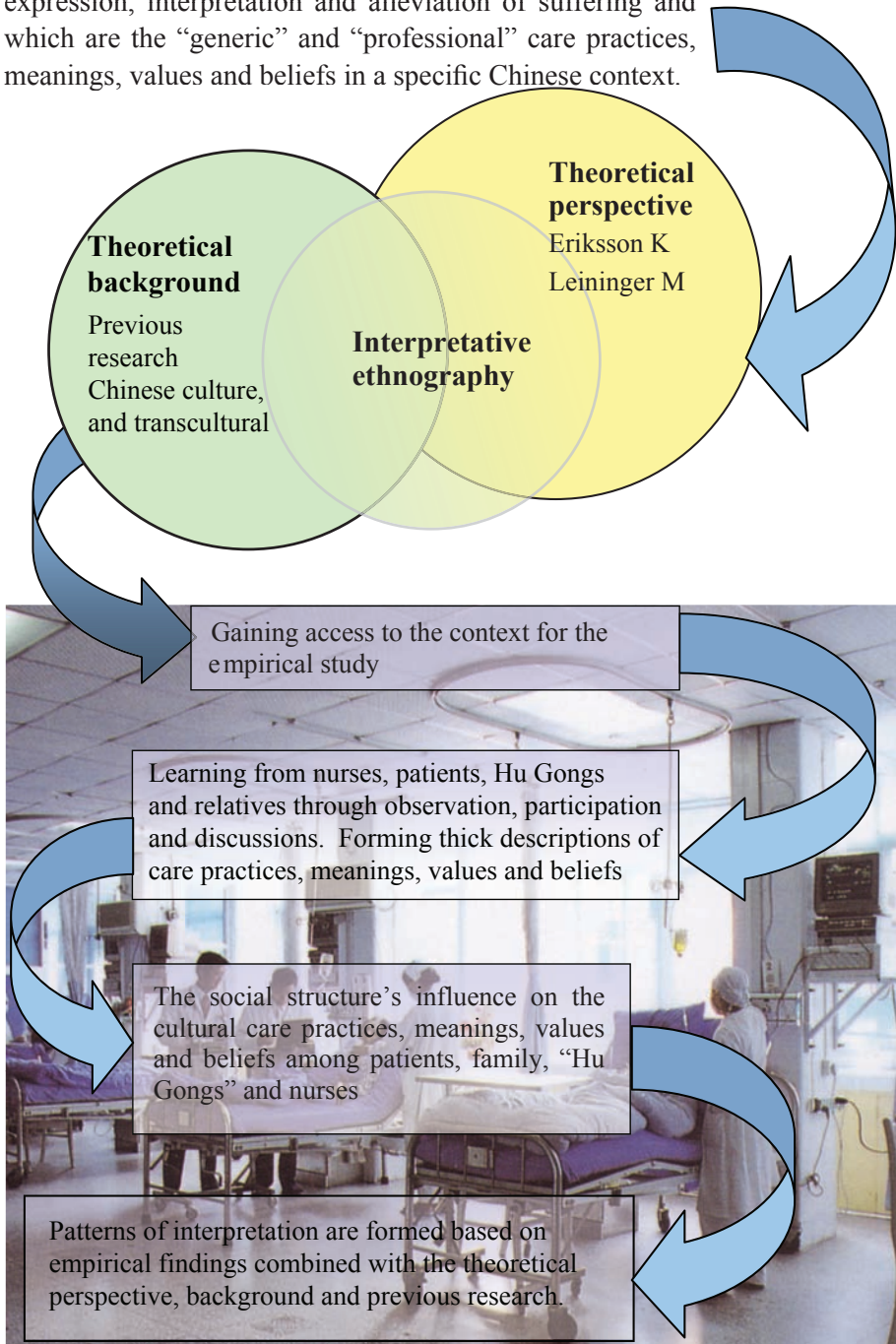


Figure 1. The research design.

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In figure 1, presented above, the research design is outlined. The design should be read from top to bottom and the arrows show the direction of the process of the study starting with a short description of the aim of the study. The aim guides the theoretical and cultural perspective and influences the choice of method. The empirical part of the study has a photograph from a hospital in China as a background. The photography is from the information brochure of Affiliated Union Hospital, Fujian Medical University (2005). The picture places the study in the hospital environment. The hospital setting has a culture of its own, but is also influenced and guided by the general culture surrounding.

Gradually a pre-understanding is gained through developing a theoretical perspective, earlier research and by learning from the people. The culture is the context, with social structure dimensions, where the suffering person, the relative and the nurse share life. The people in the culture form the practices, meanings, values and beliefs which guide how care and caring are approached and carried out. The empirical part begins with data collection focusing on the practices of the care and caring which aim to alleviate suffering. It continues with an analysis of the data where values and beliefs are discovered (“thick descriptions”), and concludes by combining the empirical data with the theoretical perspective and background, forming patterns of interpretation and assumptions regarding culture, suffering, care and caring.

## BACKGROUND

### 2. Theoretical perspective of the study

Two major directions, within nursing research can be seen; Caring science and Nursing science. Caring science encompasses human science orientation, human caring processes, phenomena and experiences. Nursing science is directed towards nursing and its profession. The current study's theoretical perspective has its starting point in an autonomous Caring Science<sup>4</sup>. The cultural perspective is adapted as a complement. Culture and its impact on care and caring as well as the experience, expression interpretation and understanding of suffering are of interest.

Fredriksson (2003) defines the theoretical perspective as choosing a way to approach, focus on and describe what you want to see. The theoretical perspective is formed by the understanding of the human being, suffering, caring and cultural care and is a foundation for the interpretation and understanding of the suffering human being. The focus of this study lies on the patient, relative and nurse, and the human being who is an entity of body soul and spirit. This way of viewing human being is included in the first basic assumption of Eriksson's (2001) theory of caritative care. Leininger (2005a) also uses the term "human being" in her assumptions underpinning the theory of Culture Care Diversity and Universality but including the cultural perspective in the description.

Assumptions, which form an understanding of caring and suffering, can be found in Eriksson's theory of caritative caring<sup>5</sup>. The theory of caritative caring emanates from the fundamental structure of caring, which is seen in the relationship between patient and caregiver. A caritative caring practice presupposes presence in suffering both by the sufferer and the co-sufferer (caregiver) and suffering is to be shared in the alleviation. Assumptions regarding culture care can be found in Leininger's theory of Culture Care Diversity and Universality (Leininger, 1991, 1995, 2002b, 2005a). Elements of the two above mentioned theories form the basis of the theoretical perspective of the study.

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<sup>4</sup> Caring Science at Åbo Academi University has since 1987 been systematically developed under the guidance of professor Eriksson as an autonomous science focused on developing the fundamental elements of a science, with an ontology, epistemology and methodology of its own (Eriksson, 1992, 2001, 2002; Lindström, Lindholm & Zetterlund, 2006).

<sup>5</sup> The development of the theory of caritative caring can be found in publications by Eriksson stretching from 1987 – 2006 (1987, 1992, 1993, 1994, 1995, 1997, 2002, 2006).



## Care, caring and culture care

Care and caring are not only the professional's task and mission, the family caregivers surrounding the sufferer are equally important. Leininger (1991) and Eriksson (1987) both maintain that professional care carries elements of generic or natural care. There is nonetheless a vital difference between generic (natural care)<sup>6</sup> and professional care. Generic care is usually delivered by non-professionals, while professional care is delivered by professionals, but can nevertheless carry elements of generic care. According to Leininger (1991) generic care can be the epistemic and ontologic basis of professional nursing knowledge. This approach can lead to a culturally congruent approach to care. Caring exists in a relationship<sup>7</sup>, a community, where the patient's suffering and the alleviating of this suffering is the unifying focus. According to Leininger (1991, 2005a), care is essential to curing and is the core of nursing and there can be no curing without caring. However caring does also exist independently, without leading to curing. Both generic and professional caring are based on an understanding of cultural patterns and caring is essential for wellbeing, health, growth and survival. Human care is what makes people human, gives dignity to people and inspires them to get well and to help others (Leininger 1991, 1995, 2002b, 2005a).

People exist in relation to others, and the social perspective is visible in Leininger's theory of Culture Care Diversity and Universality (2005a). Leininger (1991, 37) states that "*since human beings are born, live, become ill, survive, experience life rituals, and die within a cultural care frame of reference, these life experiences have meanings and significance to them in any given culture or subculture*". This makes it necessary to take culture in consideration when caring for the suffering human being. The view of the social structure dimensions described in the Sunrisemodel by Leininger (1991, 2002b, 2005a) is a tool for learning to know the patient's culture. The social structure dimensions include religion (spirituality), kinship (which can be described as social ties), legal issues, education, economics, technology, political factors, philosophy of life and cultural values and beliefs with gender and class differences. These

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<sup>6</sup> Eriksson (1987) describes "natural basic care" as expressed through tending, playing, and teaching in a sustained caring relationship, and natural basic care is included in the assumptions that underpin the theory of caritative caring found in Eriksson (2001). Generic care and natural basic care carry same idea, the learned, transmitted knowledge non-professionals use when caring for each other.

<sup>7</sup> The relationship in caring is discussed by several nursing theorists and caring is seen as a way to help people to become what they are meant to be (Mayerhoff, 1971). Caring is also connected to human survival (Watson, 1993), while Roach (1992) and Halldórsdóttir (1996), Halldórsdóttir and Hamrin (1997) link caring to ways of being. By caring for people the carer can alleviate suffering and support the sufferer towards healing by his/her actions, or by non-caring actions destroy and create more suffering for the sufferer. The relationship in caring has a significant effect on healing.

factors need to be understood as they directly influence health and wellbeing. Leininger's idea of placing health and wellbeing, and consequently also suffering, in a social context, changes the focus of suffering and caring from a procedure in a relationship between individuals to a procedure placed in a cultural context. It necessitates the inclusion of the social process in the understanding of the person's suffering and need for care. Eriksson (2001) sees the caring relationship as forming the meaningful context of caring. She derives its origin from the ethos of love, responsibility and sacrifice, which is described as a caritative ethic, where a deep motivation to do good to the other is present.

Culture and care are both independent from each other and linked together. Culture care is necessary for culturally congruent care, and culturally congruent care is the goal of nursing care according to Leininger (1991, 1995, 2002b, 2005a). Culturally congruent care is dependent on cultural competence. Caring can only take place when care values are brought to the surface and caring is delivered in an appropriate, safe and meaningful way. Culturally based care is essential to caring, curing and healing. Culture care concepts, meanings, expressions, patterns, processes and structural forms of care vary transculturally but with some universalities. Professional and generic care vary transculturally and culture care values, beliefs and practices are influenced by and embedded in the worldview, in the culture of a people. This worldview influences on the care, both the professional and the generic, delivered individually by nursing staff, relatives and institutions. This brings forward the need for cultural competent care that is influenced and guided by the patient's worldview<sup>8</sup>.

## Understanding suffering

Suffering can be seen as a form of struggle and dying, according to Eriksson (1994, 2006). The suffering person is struggling for his/her life; a struggle which goes on in the midst of suffering and the human being can either remain in the suffering or, alone or with help of others, find a way out. Suffering can be viewed as a drama of life and death, and the suffering human being lives through different phases in the course of her own drama of suffering. The sufferer does not act out the drama alone, there are other people surrounding the sufferer who have different roles in the drama. The confirmation of suffer-

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<sup>8</sup> "Culture care" and "culturally congruent care", are both concepts that are linked to the founder of "transcultural nursing", Leininger. She coined the concept "culturally congruent care", and it can be found in her writings from the 1980's onwards (Leininger, 1980, 1985, 1991, 2002b, 2005a). Culture care is described as *"the cognitively learned and transmitted professional and indigenous folk values, beliefs and patterned life-ways that are used to assist, facilitate or enable another individual or group to maintain their well-being or health or to improve a human condition or life-way"* (Leininger, 2002b, 57).

ing is both an outer and an inner confirmation. To confirm the suffering is to communicate to the sufferer: “I see you and I understand”, which opens up for comforting the sufferer.

The sufferer needs to come to terms with the suffering because otherwise the sufferer is not receptive to comfort and to alleviation of suffering<sup>9</sup>. To be in suffering is to acknowledge the suffering but to be unable to fully relieve the suffering. Reconciliation with suffering is a struggle between hope and hopelessness; between life and death. If life wins the battle, the human being can ascribe a meaning to the suffering. The drama of suffering can be seen as a spiral which begins with the human being confirming his/her suffering and continues with the process which leads to acceptance of being in suffering. When reconciliation of suffering occurs, the human being can ascribe suffering a meaning, and continue with (new) life or death (in peace with herself). If no reconciliation of suffering occurs, the person is in a state of suffering which might become an unbearable situation (Eriksson, 1992, 2006; Wiklund 2000). Suffering and health belong together. Health can be seen as an entity of soundness, wellbeing and healthiness and it can exist on different levels. Health can co-exist with suffering, unless the suffering is experienced is unbearable. Health is the ultimate goal when living through the drama of suffering (Eriksson, 1994, 2006). Health and suffering can be seen as reflections of each other.

## **Suffering related to culture and cultural patterns**

Cultures differ from each other and specific features can be found in every culture. The values that underpin a culture vary and there are also similarities between cultures. Culture shapes patterns for daily living and is shaped by people through their daily life. Cultural phenomena distinguish human beings from nonhumans (Leininger, 2005a). Becoming human is becoming an individual and we become individuals under the guidance of cultural patterns, which are historically created systems of meanings which give form, order, point and direction in our lives. The cultural patterns which are involved are not general but specific, a set of notions concerning what human beings are like. The human being is to be defined neither by his innate capacities alone, nor by his actual behaviours alone but rather by the link between them (Geertz, 2000a).

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<sup>9</sup> Fredriksson (2003) who used the idea of suffering as a drama described how suffering can be obscured and hidden behind a façade. The façade has two functions, to protect the sufferer from his/her own suffering and to hide the suffering from others. The façade both protects and creates suffering since the sufferer cannot get in contact with his/her own suffering before the façade cracks and the suffering is obvious to all. Fredriksson's research is done in the context of psychiatry, but his results can act as an inspiration to understand other fields in nursing care.

Eriksson (1994, 1997) describes suffering as a unique experience of the human being and as a natural part of life. Consequently, the caring perspective of the patient's world can only be understood from the perspective of suffering (Eriksson, 1994, 1997). The cultural structure which forms patterns is integrated in the individual and consequently different for everyone. Therefore there is no single picture of how suffering is experienced, expressed and understood, but rather the opposite; there are individual expressions, understandings and ascribed meanings to suffering. However the individual picture can be more easily understood when one understands the general picture, which is shown in the society in question. The human being interprets the world based on cultural structures, patterns and the worldview that the culture shapes. Caring for the suffering human being, the need for care and the need for caring for each other are universal. The forms nevertheless differ, depending on the culture that shapes our worldview. Both culture and care need to be understood and actualized in a diverse and in a specific cultural context.

Care has cultural and symbolic meanings and care and caring are essential parts of a culture. Care is also the essence of nursing and it makes nursing what it is, or could be, concerning healing, increasing wellbeing and helping people to come to terms with disabilities and dying (Leininger, 1991, 1995, 2002b, 2005a). Suffering is a universal experience shared by all human beings (Eriksson, 1994, 2006), but the expression and understanding of suffering is linked to the specific cultural system and to the meanings that people ascribe to the suffering. The way we interpret, understand and express suffering is linked to the cultural practices, meanings, values and beliefs that we have. The expression of our suffering is deeply rooted in the worldview that surrounds us<sup>10</sup>.

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<sup>10</sup> Suffering is a part of human life, it is evil but human beings can ascribe suffering a meaning (Eriksson 1994), a statement also found in Geertz (2000a) who points out that human beings can ascribing meaning to experiences and form the culture which gives a model for how to act and react. Following this, suffering can be ascribed different meanings depending on the cultural context where it occurs.

### 3. Previous research

The research area is extensive and the focus, when compiling previous research, is on how suffering is described, experienced and expressed, on caring for the patient seen as a suffering human being and on cultural competence. The literature search has been limited to publications from 1995 to 2007 and mainly references from this era are used. The literature search was done over an extended time (2000 – 2007). The databases CHINAL<sup>11</sup> and Academic Search Premier<sup>12</sup>, have been used. The keywords which have been used are *cultural competence, communication and inter/trans/cross cultural nursing/caring relations, nurse/patient, nursing and suffering, suffering and caring/nursing models, theories, social and suffering nursing/caring, family, generic/natural care, carer, caregiver, China, culture, caring needs, trans/cross/inter/multi cultural care/nursing*. Thousands of articles were found. The keywords were used in different combinations. Literature was also found through the snowball method, which means that additional literature was found based on references from previously obtained articles.

#### Suffering as a motive for caring

In the present study, a perspective on suffering as a broad concept covering different conditions is adopted. A description of suffering viewed from a social and cultural perspective is of interest in this study as well as the perspective of the suffering human being, commonly seen as the patient. Not only the patient suffers, nurses and relatives also carry the burden of suffering. Consequently their voice is also heard. Suffering is a core concept in caring science, and it has been the focus of many nursing researchers. When searching for research concerning suffering, several hints were found describing the experience of patients suffering from a specific disease and caring actions designed for a specific illness. These articles are excluded in this review. The research used in this review is mainly from the Western world; Europe including the Scandinavian countries, Finland and North America.

#### *Descriptions of suffering*

Suffering is a central concept in caring science, and it is linked to the words “empathy” and “sympathy”, since the Greek word “sum” means “with” and

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<sup>11</sup> CINAHL is a source of full text articles for nursing & allied health journals, with more than 520 journals indexed.

<sup>12</sup> Academic Search Premier is a multi-disciplinary database which provides full text for nearly 4,500 journals, including full text for more than 3,600 peer-reviewed titles. Academic Search Premier is updated on a daily basis via EBSCOhost.

“*patheia*” means “suffering” (Rodgers & Cowles, 1997). Compassion is also etymologically linked to the word suffering since in Latin “*cum*” and “*passio*” mean “to suffer” (von Dietze & Orb, 2000). According to Georges (2002), the Western understanding of suffering is mainly shaped by the description of Christ – the ultimate sufferer. Christ endured undeserved individualized suffering, with the added aspect of enduring suffering for a redemptive cause. The words suffering and patient are similar to each other not only from the standpoint of etymology, but also from the standpoint of nursing.

Pain and suffering are linked to each other (Cassell, 1996; Eriksson, 1993, 1994; Sachs, 1987; Öhlen, 2001), although they are not synonymous. Chung, Wong and Yang (2001) describe pain as not exclusively physical. Pain has also social and psychological dimensions. Pain and suffering are even used interchangeably in nursing research and according to Rodgers and Cowles (1997), suffering is not a well-investigated area in nursing and it is often discussed indirectly, as it is associated with pain. Suffering can be seen as a part of the ontology of caring science (Eriksson, 1993, 1994, 1997) or used in symptomatic descriptions related to pain, illness, disease and different ways to alleviate pain (Sachs, 1992).

Suffering is described through concept analysis by both Rodgers and Cowles (1997) and Eriksson (1994). Rodgers’ and Cowles’ findings show that suffering is individualized, subjective, complex, that it has a meaning and is intensely negative, while Eriksson finds that suffering has two “faces”. It is negative but might lead to a meaning or reconciliation when living “through” the suffering, and is connected to struggle and a “dying”. Eriksson (1994) Wiklund (2000), Morse (2001) and Georges (2002) describe suffering as encompassing different experiences related to threat, loss or violation of “the self”, and if suffering can be related to some kind of personal meaning it is possible to alleviate it. Suffering is something natural in human life, and it is evil (Eriksson, 1994). Suffering can be a sign for a demand or a lack and it is also present in compassion, when suffering with or for somebody else.

It is difficult to explain and describe suffering, since it is an abstract concept, and the limitation of words to describe the experience become problematic (Frank, 2001; Rodgers & Cowles, 1997). According to Frank (2001), sufferers may also discuss suffering indirectly by using words like illness, discomfort, anguish, distress, tournament, pain, heartache, misery, anxiety, affliction, grief, sadness, fear, loneliness or other words, which can make understanding the suffering experience difficult. Suffering has been viewed as a response to losses: the loss of a pain-free existence, the loss of health, the loss of dignity,

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the loss of movement, the loss of an anticipated future, the loss of another and the loss of self (Charmaz, 1999; Eriksson, 1993, 1994; Frank, 2001; Georges, 2002; Morse, 2000, 2001; Smith, 1998).

Two models are mentioned which aim to describe suffering as an experience in which different phases can be observed are mentioned, namely Eriksson's and Morse's models of suffering. Eriksson (1994, 2002, 2006) uses drama<sup>13</sup> as a metaphor when describing the different phases of suffering and claims that it is a process which the sufferer can go through and find reconciliation. The different phases are subjective and can be viewed as a spiral where the sufferer firstly has to acknowledge the suffering and also be confirmed in the suffering to be able to be in it and finally go through it. When reconciliation is achieved the sufferer can ascribe suffering a meaning. To suffer is to struggle and the struggle is between life and death. Suffering is seen as the reason why nursing care takes place and as a "lived experience". Morse (2001) has created a praxis theory of suffering where she identifies two broad and divergent behavioural patterns of suffering; emotional suppression or enduring and emotional suffering. These states are not only distinct, but also diametrically opposite. Enduring is described as a condition, which is not directly connected to suffering, but which precedes suffering.

Morse and Doberneck (1995) found a connection to the enduring phase in their study concerning the concept of hope. The patients waiting for transplantation, or diagnosis, endured the suffering so that hope could be sustained. The patients who were aware of a life-threatening situation were constantly "hoping against hope". According to the above, the enduring phase can sustain hope, but Morse (2001) also says that when one has suffered enough, hope gradually begins to emerge and it can bring the sufferer from despair to a reformulated self. To move from despair to a reformulated self one needs the phase of emotional suffering. This can be interpreted as the notion that the enduring phase sustains hope but the phase of emotional suffering can bring the sufferer to a reformulated self where hope can emerge. Morse and Carter (1996) and Morse (2001) describe that a person who suffers, can move back and forth between enduring and suffering, according to his/her own needs and according to the situation. In a caring relationship, the enduring person should not be forced to enter the stage of emotional suffering before the sufferer is ready to take the step since the enduring state is focused on the present, and the past is blocked out and the suffering stage is very emotional.

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<sup>13</sup> Eriksson (1994), followed and further developed by Eriksson (2001, 2006), Fredriksson (2003), Lindholm (1998), Råholm (2003), Rehnsfeldt (1999) and Wiklund (2000).

### *Suffering seen from a social perspective*

According to Georges (2004), there is a need for a shift in the epistemology of suffering, a philosophical shift which allows nursing science to expand its horizons of understanding suffering and go beyond a Eurocentric and apolitical model. The Eurocentric, apolitical model describes suffering as an unconnected, individual experience. In nursing science it is necessary to understand that suffering has been and is being perpetrated by nurses and that the nurses continue to promote suffering when remaining silent about the political realities that cause suffering. Kleinman, Das and Lock (1997) also describe suffering as a result of political, economic and institutional power and then name it "social suffering". The authors view suffering as a political and cultural issue. The central thesis of the text is that suffering is a social experience shaped by political realities, which is in opposition to many other views of suffering. Suffering has, in the Western cultures, been portrayed as a response to a discreet event that people experience in an apolitical, acontextual universe.

Social and cultural factors are thought to have an impact on health problems in a Chinese context. This is discussed in a study by Hsiao, Kilimidis, Minas and Tan (2005) who focus on mental health care. Chinese people's mental wellbeing is frequently associated with stress arising from family, environment or intergenerational relationships. This is linked to the Chinese society where an individual's sense of self is deeply rooted in social relationships. An individual is obligated to do whatever it takes to maintain a well-functioning family, which is in contrast to the Western culture which emphasizes an individual's autonomy. The expression of suffering is dependent on the situation where the suffering occurs. According to Morse (2001) the question of enduring or suffering is a process of appropriate behavioural norms; a person might endure in public but suffer in private, or one may suffer in front of some family members but hide suffering from others. Charmaz (1999) brings forward similar findings when saying that suffering may slip into the background when pressing needs and other people take priority, and this might occur because the person is unaware of how much he or she suffers.

The expression and interpretation of suffering can be dependent on moral status, education, and on the individual's ability, or inability, to be an advocate and speak the same language as the health care personnel according to Charmaz (1999) and Cope (2000). The suffering of someone with high moral status is assumed to be significant face value and awarded unrequested attention when illness first begins or dramatically increases. The suffering of someone with low moral status may be ignored or minimized and pain in minority groups is



not well controlled for example. Social status might therefore be an important factor affecting how the sufferer manages to go through suffering. Gender, class and ethnicity can also play a role in shaping the suffering experience. According to Calvillo and Flaskerud (1991), nurses and patients assess pain differently regardless of cultural background. Both nurses and physicians tend to underestimate the pain of their patients, compared to the patients' assessment of pain. However, the ethnicity and culture of the patient influence the difference between the patient's and nurse's assessment. The culture of the nurse also influences the interference of patients' physical pain and psychological distress.

Social suffering is not only discussed from a political, economical and institutional viewpoint. Charmaz (1999) discusses suffering as "a part of the self" – that makes suffering social. Suffering shapes social relations but might also limit the social world since it can dictate daily life and shape lasting meanings. It can lead to either development or diminishing of "self". It can be a path to finding resolution and wisdom or a route to sinking into depression and despair. Rehnsfeldt and Eriksson (2004) investigated how the caring encounter can create meaning in communion and thereby alleviate suffering or make it bearable. To confirm the suffering is to give the sufferer a message that his/her suffering is seen (Eriksson, 1993; Fagerström 1999; Wiklund 2000). The expression of suffering takes place when there is somebody to see it and confirm it, which makes suffering social (cf. Charmaz, 1999; Eriksson, 1994, 2006; Fredriksson, 2003).

### ***Suffering caused by lack of culturally sensitive caring***

The expression and experience of pain in culturally diverse settings is a widely researched area and Davidhizar, Shearer and Giger (1997) found that members of different cultural groups express pain differently. The caregiver might unconsciously cause a patient suffering by acting in a way that is not culturally competent; it is insensitive to the patient's cultural values. Nurses work intimately with patients and families who are experiencing suffering, and consequently the nurses need transcultural communication skills in order to be able to support the sufferers. Culture influences a person's perception of pain (Andrews & Herberg 1999; Gieger & Davidhizar, 1999; Leininger, 1997b, 2002a; Spector, 2000) and Lash (2000) stresses that with the increasingly multicultural society, we need a culturally sensitive pain assessment.

Shire (2002) investigated discrepancies in race and ethnicity, gender, culture and illiteracy in the light of pain medication. She found that there are differ-

ences in alleviation of pain depending on the factors mentioned above and Charmaz, (1999) reports similar findings. Acello (2001) and Gernot (2000) discuss the language of pain, and verify that pain has a language of its own, and different cultures express pain by using different words and signs, which also can be seen in the use of different metaphors, according to Petersen, Heesacker and Schwartz (2001).

Cultural knowledge is necessary for the nurse to correctly understand the patient's need for care. Culturally insensitive care can cause suffering, described by Leininger as "cultural pain" (1997b; 2002a). Cultural pain is a relatively unknown concept in caring science. Searches in databases gave no findings when "cultural pain" was used as the keyword. When "culture" and "pain" were used several sites were found, most of the articles concerned physical pain, different cultures and pain assessment. When combining "culture"/"cultural suffering" or "culture" and "suffering" as keywords several hundred articles were found. Commonly the studies concern suffering from a specific disease and these kinds of articles are excluded from this study. According to the literature search the concept of "cultural pain" is mainly used by Leininger but Hubbert (2002) also uses the concept when discussing cultural pain occurring in nursing management for example, when a nurse manager is not familiar with a nurse's cultural background and values and unintentionally causes the nurse cultural pain. Suffering and cultural pain are linked to each other, although pain generally refers to physical pain.

Cultural pain includes suffering, and brings a new dimension to suffering, namely the suffering caused by culturally insensitive caring such as cultural blindness and imposition (Leininger, 2002a, 2002c). Cultural pain can be seen as a result of another person's words or actions which are experienced as hurtful, embarrassing or insulting. This explanation coincides with Eriksson's description of the domain of suffering related to (lack of or inadequate nursing) care (1994, 1997, 2006). Cultural offenders often lack knowledge about the culture in question and are unaware that their words and actions are hurtful to others. Martin and Belcher (1986) investigated correlations and trends among different groups regarding attitudes towards pain, caring for the dying patient, and disease modality. They found that cultural values were of great importance to the nurse's attitudes towards the patients' caring needs.

Culture is a potent force in shaping beliefs, behaviours, and meaning concerning pain. In health care contexts, there may be a conflict between care and cure and also differing perceptions about the role and status of nurses that impinge on the provision of pain relief. The health care provider must understand pain

from a cultural perspective, especially today when we are living in a multicultural world. (Davidhizar, Giger & Shearer, 1997). It has been documented that nurses do not effectively manage pain, and several contributing factors have been identified by Warden, Carpenter and Brockopp (1998). Because pain and suffering often coincide, it seems likely that nurses' beliefs about suffering could affect their management of pain. Nurses' underestimation of suffering can be seen as a potential barrier to effective management of pain.

The social suffering described by Kleinman, A and Kleinman, J (1997) can be interpreted as one aspect of cultural pain. Culture and cultural pain have their roots in the social context of the person who is suffering. Hanssen (2002) and Öhlen (2001) discuss difficulties that can be encountered in alleviating suffering and delivering good care, when differences in culture obstruct mutual understanding. Eriksson (1993, 1994) describes suffering caused by (nursing) care as a violation of the patient's dignity. Cultural blindness can also be seen as a violation of the patient's dignity. If nurses lack cultural competence, the care they provide will be impaired by cultural blindness and imposition. This might lead to violation of dignity and increased suffering caused by nursing care, as well as existential suffering.

### ***Communicating suffering***

In nursing research the term communication is commonly used to describe the transaction between nurse and patient/family. Communication is a broad concept and Fredriksson (2003) in his research concludes that the term conversation (meaning verbal communication) is more suitable to use in praxis and in clinical caring science than the term communication, when describing the verbal communicative caring procedure between patient and nurse. Hemsley, Sigafos, Balandin, Forbes, Taylor, Green and Paramenter (2001), Johansson, Oléni and Fridlund (2002) and Stensland and Malterud (1998) see communication as a learning situation, providing different ways of giving the patient information, to bring a message to the patient and help the patient take part in the nursing process and decision making. Kruijver, Kekstra, Bensing and van de Wiel (2001), Manderson and Allotey (2003) see communication as a caring relationship and as a way of caring for patients, and Graber and Mitcham (2004) describe communication as showing compassion in a close relationship. Communication can also be described as seeing the unique patient in the encounters (Davis 2001). Communication is seen in the encounters between patients and nurses and in the importance of understanding the patient's different ways of expressing their suffering (Takman & Severinsson, 1999). Communication can be viewed as a kind of behaviour which can be divided into

instrumental behaviour, used when informing about illness and treatment, and affective behaviour, used when showing respect, giving comfort and conveying trust. Kruijver et al (2001) investigate the balance between affective and instrumental communication employed by nurses in an oncological setting. They found that nurses predominately focus on conveying information and employ instrumental communication and giving information.

Sumner (2001) discusses that problems can occur when one part of the communication is not paying attention, or does not understand the message. However, communication is more than just the transfer of information; it is how information is conveyed, how it is received and how it is responded to or understood. Health care professionals generally assume that their perceptions and assessments of their patients' health status are accurate and that they are congruent with those of the patient and other health care providers. These discrepancies are of particular concern to nurses because they may interfere with the provision of quality patient care. Poor communication, non-compliance with the treatment regime, inadequate or unnecessary treatment, and ethical problems can be outcomes of discrepancies in perception. These can result in poor nursing care. Language, both verbal and non-verbal, is of crucial importance in caring for a suffering human being. The carer needs to give correct signs and should not act based on misinterpretation of the patients caring needs. Morse (1996, 2001) discusses this related to the enduring – suffering phases, and how important it is to let a person just endure, and not try to bring the person to the emotional stage of suffering before the person is ready. Doing this might cause increased suffering. This demonstrates even more clearly the importance of culturally competent care.

Moore, Chamberlain and Khuri (2004) investigated how suffering is communicated among a small sample of patients in primary stage head and neck cancer. They found that patients under-report their experiences of suffering to their clinicians. The under-reporting may be due to the patients fears; fears of being further diminished by the disease, fears of addiction and fears that they will not be able to cope with the additional loss associated with this disease. Fredriksson (2003) touches on the hiding of suffering when he describes, in a psychiatric setting, how the sufferer might keep up a façade when not showing signs of suffering and not even admitting to it. Talking about and exposing the suffering seems to be an important part of healing. To communicate suffering is important here. Melvin and Heater (2004) discuss a new paradigm for nurses when listening to the suffering human being. The witnesses of suffering can be difficult to see and the message of suffering can easily be mixed up with other messages.

Nonverbal communication is important when expressing emotions. It is partly hereditary and partly learned, and can therefore be regarded as partly culturally bound. Non-verbal communication is said to be more honest than verbal communication. Non-verbal communication is communicated through facial expression, tone of voice, eye contact, head movements, body movements, space and physical contact. Participants who in communication tend to evaluate the discussion based on how well the other person communicates and how they are affected by the communication. Nonverbal communication plays an important role, since as much as 55 - 97% of the total impact of communication is the result of nonverbal factors (Caris-Verhallen, Kerkstra, de Gruijter, & Bensing, 1999; Newman, 1998.) Understanding the patient's message is not necessarily culturally bound, misunderstandings could just as well occur within the same culture. According to Roux (2002) speaking the same language does not guarantee a successful communication; there are several other factors influencing the communication. However, misunderstandings occur less frequently in communication between parties from the same culture.

### *Ascribing a meaning to suffering*

Suffering has to have a meaning to be bearable, and it is the sufferer that ascribes the suffering a meaning. Rehnsfeldt (1999), in his study of women suffering from breast cancer, focuses on the "drama of suffering" and states that the patient must be open to suffering and despair in order to "afterwards" achieve renewed health through finding meaning in life by seeing life and suffering from a new and wider perspective. Suffering may also be caused by sort of meaning the patient ascribes to the illness (Cassell, 1996), or by loss of mobility and change of lifestyle (Morse & Carter, 1996). The person who is suffering is filled with sadness. When one has "suffered enough" hope begins to emerge and the person can make plans and set up goals again (Morse 2001). Starck (1992) sees suffering as a process of repair. Moving away from suffering is getting on the road of hope (Lohne & Severinsson, 2005) (cf. Jones, Zhang, Xinwei, Meleis, 2003). This can be interpreted as an explanation to the fact that suffering is a negative experience but that the human being can nevertheless ascribe it a meaning - let it influence life and change life paths. Hope is essential for this change of life direction. Wayman, Barbato and Gaydes (2005) use Watson's theory of self-transcendence when discussing how self-transcendence can occur through suffering. Transcending suffering allows a deep appreciation of life, even when the suffering situation itself is resolved. Perreault, Fotehrgill-Burbonnais and Fiset (2004) describe the experience of suffering as "five seasons of the tree of life". The suffering human being is closely linked to nature and the patient describes her suffering cycle as the seasons of a tree,

starting from when leaves fall and leading up to the healing process which is represented by the blossoming of the tree.

### ***The ethical imperative in encounters with sufferers***

Sumner (2001) and Fagerstöm (1999) see caring in nursing as a complex warp and woof of the tapestry of the relationship between two or more people. The moral ideal of a specific health/illness situation is created when the parties involved contribute their own history and cultural background. According to Fredriksson (2003) the carer has two different possibilities of viewing the sufferer; either as weak, and in need of strength from another person, or as occasionally weak but with potential to regain health. The carer's view of the sufferer directs the carer's caring actions. Sumner (2001) continues by discussing the relationship and finds that it has cognitive, emotional and attitudinal elements and that the communicative action has a positive outcome if each part has a sense of fulfilment or validation. This can occur when the patient acknowledges that his/her needs have been met satisfactorily and the nurse is rewarded, having helped the patient to achieve this.

The patient has to be open to share the suffering in an encounter with the carer, and consolation can be a caring act aiming at alleviating suffering. Consolation presupposes space and time and a communion between patient and nurse truly present (Norberg, Bergsten & Lundman, 2001) and it can be "the little extra" mentioned by Arman and Rehnsfeldt (2007). They discuss in their study the patients' need to be seen in his/her encounters with health care professionals. Nurses regard this as an ideal and a potential road to fulfilment in their work, if the right entry to the patient is found. The nurse can make a difference by the "little extra" which is to notice and see the patient and meet the patient in his/her caring needs. The "little extra" is a sign of *caritas*, the unselfish love and expressed in actions.

Communication, to see and react to others' suffering is discussed in ethics. Nortved (2001) discusses, how the other person's pain and suffering may reveal your own suffering. In clinical nursing, it is important to understand how this encounter between professional knowledge and moral values forms the basis for clinical action, making it morally as well as professionally proper. Sensitivity to vulnerability is a qualification that is a crucial part of clinical knowledge in the sense that it alerts clinical sensitivity altogether (Nortvedt, 2003). The reaction to the other's suffering is an ethical act and it differs depending on cultural belonging. Cultural belonging also seems to influence the expression of strong emotions, a result found by Papadatou, Martinson and Chung (2001),

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who describe Greek and Chinese nurses in their expression of grief and how they attribute meaning to childhood death.

The ability to listen to your own inner voices facilitates the ability to listen to others (Jones, 1999), and the patient's voice needs to be heard, the patient's subjective experience forms the expression of suffering (Nortvedt, 2003). It is important that nurses have knowledge and understanding of the suffering human being in order to ease suffering and Nåden (1998) discusses this under the title of caring as an art. Sæteren (2006) in her research concerning suffering among patients in palliative care, claims that suffering related to the receipt of care seems to occur when the encounter between the patient and the nurse is not based on the patient's experience, and the expected respect and sensitivity for the existential situation of the patient is absent.

Differences in paradigm between the nurses and the suffering patient can in some cases, cause more suffering than the disease itself. The suffering related to health care becomes evident through avoidance, neglect and uncaring (Arman, Rehnsfelt, Lindholm & Hamrin, 2002; Arman, Rehnsfeldt, Lindholm, Hamrin & Eriksson, 2004). Eriksson (1994, 2006) describes three different modes of suffering; suffering caused by illness, suffering caused by (nursing<sup>14</sup>) care, and existential suffering. Suffering related to (nursing) care is characterized as a violation of dignity, neglect and uncaring. The nurse's interaction with the patient has been the domain of inquiry for Halldórsdóttir (1996) and she has pointed out five different ways for the nurse to be with other people; 1) a life-destroying mode, 2) a life-restraining mode, 3) a life-neutral mode, 4) a life-sustaining mode and 5) a life-giving mode. The life-destroying mode of being with another is the most inhuman mode of being with another (the patient). How nurses understand, act and interpret the message of patients' caring needs is of importance for the care of the patient. Situations and encounters in health care can, from the patient's perspective cause or increase their suffering rather than alleviate it (Halldórsdóttir & Hamrin, 1997; Winman & Wikblad, 2004). Hsiao et al (2005) discuss the Chinese patients' experiences of suffering and state that understanding the patient's culture helps nurses to understand how suffering is shaped by culture. To be culturally empathic, nurses need to have a cultural understanding and the ability to identify the cultural elements of interpersonal harmony – elements such as filial piety, loss of face, guilt or shame. The nurses' expressions of cultural empathy help them to be able to feel as their patients feel and thereby respond appropriately to their patients' needs.

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<sup>14</sup>Eriksson (2006) mention suffering caused by care, but in the description of the suffering caused by care it is merely a non-caring action or a suffering due to violation of dignity acted out in nursing care.

### ***Relatives' and nurses' suffering***

The context of the patient's life involves not only the situation in which the patient is cared for, but also the whole life situation of those involved, the history and the future, the family and the group/s to which the sufferer belong. This is described by Tapp (2001). Cultural patterns regarding how suffering is expressed and expected to be met are also important. Suffering must be studied from a holistic perspective where the whole person is placed in the context of life. It is not only the patient him/herself that suffers. Relatives and people who care for the patient are also affected by the suffering, the change from independency to dependency and the increasing vulnerability that the patient experiences. The patients and the relatives talking or not talking about the situation may be a protection from showing vulnerability. When the sufferer does not talk about his/her own suffering, the person seek to protect him/herself from the change in value that follows the transformation of becoming a "sick person" and it is difficult to reach these people.

Most research discusses the caring relationship between two people; the patient and the nurse. Leininger (1991, 1997a, 2002b, 2005a) in her theory emphasizes the family, the group, as one part of the caring relationship. Tapp (2001) stresses the same thought when discussing the context in which the suffering occurs and the people who are involved in that context. Smith (1998) discusses similar thoughts, and writes that suffering is often viewed as a subjective experience connected to the context in which it occurs. The patient is commonly seen as the only person suffering, however the patient's family and those involved in his/her life and caring situation are also affected. Lopez (2007) in her study focuses on the relative's suffering and she finds that family members are involved in the suffering and that suffering also has a significant impact on nurses.

A model of communication concerning nurse's responses to patients who are suffering is described by Morse, Bottorff, Anderson, O'Brien and Solberg (2006). The communicative action is part of the alleviation of suffering. The essence of the nurse-patient relationship is the engagement and identification with the patient. This model has its starting point in how empathy is seen in nursing and the researchers find that little attention has been given to emotional empathy – the caregivers intuitive sensing of and response to the other's plight – and the part it plays in nurse – patient interaction. The authors found that the constant exposure to patients' suffering emotionally drains the nurse and the limitations of shared suffering must be controlled by the nurse. The human responses that are sufferer – focused are triggered by the emotional insight of



the caregiver and they are culturally conditioned rather than learned. Reactions to suffering are both spontaneous and learned and the authors stress that there is a need for adequate education in how nurses can avoid being emotionally drained in caring for sufferers. They need adequate education in how to use professional methods for being sufferer-focused in the caring actions. Morse, Whitaker and Tasón (1996) say that caregivers experience suffering as they observe unless it is the suffering of another caregiver. Caregivers may suffer as they mourn loss and death. They also suffer as they observe the changes that the illness has caused in a patient (for example a patient with Alzheimer's), or as they watch the daily struggle against pain and disability. Suffering is expressed to others and thus becomes a shared experience.

Patients are a part of the nurse's life and they influence the way the nurses live their lives. Suffering becomes a part of the nurse's life, and different methods, like disembodiment, help the nurse to keep a distance to suffering and not to become an integral part of suffering. (Maevé 1998.) Much research has been done concerning nurses' and student nurses' experience of patients' suffering. Eifried (1998) in her doctoral dissertation discusses nursing students and their vulnerability when meeting patients who suffer. She highlights the urgent need to prepare students for these situations within nursing education. Jezuit (2000, 2001) discusses suffering among nurses when caring for patients in end-of-life situations and in critical care nursing. Many of the nurses in her study talked about "taking the suffering home" with them, which indicates a transition from professional distress to personal distress, and possibly also the opposite. Jezuit (2001) suggests a system with peer support and a supportive, non-threatening environment for nurses to discuss their feelings regarding suffering and meeting patients who suffer. White, Wilkes, Cooper and Barbato (2004) found that unrelieved suffering among patients had a big impact on nurses. This personal impact of unrelieved patient suffering could be reduced through acknowledgement of the impact and better formal and informal support. Rowe (2003) describes similar ideas in her study and she describes three phases of response to suffering: mute suffering, lamenting and changing. The most important element in reducing the suffering of the healer is to reduce isolation. Isolation can be reduced by sharing suffering. Health care workers are consequently in need of support groups.

### **The patient's need for care and the family as caregiver**

The sufferer can be a patient and in literature commonly the term sufferer refers to patients. The patient's need for care is expressed differently depending on situation, culture and of course also due to individual preferences. In the

following chapter the patient's need for being seen and the family as caregiver is discussed.

### ***The patient's need to be seen and cared for***

The person who has become a patient is vulnerable and needs professional assistance (cf. Fagerström, 1999). The patient suffers from a vulnerability which is beyond the fundamental human vulnerability that arises from the ordinary social world participation. The patient enters the illness-induced interaction with a carer, hoping that his/her vulnerability will be acknowledged (Sumner 2001). Sharing the experience of suffering with a compassionate person allows the sufferer to work through and interpret the suffering. When the suffering is accepted by another with caring compassion, it can be radically transformed (Fredriksson, 2003). Patients need to be seen and there is a great deal of existential need in many patients. Arman and Rehnsfeldt (2007) in their study pose the question if "*being seen*" is a rarity in health care today. Among others, Eriksson (1994, 2006), Fagerström (1999), Rehnsfeldt (1999) Råholm (2003), Sæteren (2006) and Wiklund (2000) discuss the sufferer's expression of his/her own suffering, and it can be seen as a way of showing a need of care, to be seen and confirmed in suffering. Suffering can be seen as a message communicating caring needs, which is the topic of Fagerström's (1999) study. The basic prerequisites for understanding the patients caring needs lie in an understanding of the human being as an invisible entity. Suffering and caring as the core of nursing care are central basic categories. Another basic requirement is to understand a human being's way of being in the world. The fulfillment of caring needs takes place in a caring relationship, which in its turn occurs in a special context, the current context of life. Understanding the context of life as a whole creates the predictions for the nurse's ability to meet the patient's caring needs and to alleviate suffering so that the health processes can develop towards health and wholeness. Fagerström defines caring needs as the problems, needs and desires arising when the health problem has developed into a suffering where professional help is needed to attain health and wellbeing. Caring needs can be expressed, unexpressed, conscious and unconscious. According to the above the caring needs seem to require professional help to attain a higher degree of health, wholeness and wellbeing.

Alleviating children's postoperative pain with non-pharmacological methods is the topic of He's study (2006). The study is conducted in Fuzhou and Quanzhou in Fujian Province, China and therefore of special interest. Among cognitive-behavioral methods, He found that nurses who worked as informants

gave preparatory information as a pain alleviation method both directed to the patient and to the parents. The nurses also used imagination (e.g. asking the children to think of pleasant activities and places while in pain) and distraction (e.g. by humour, playing games and reading books and magazines) as pain relieving methods. Among the physical methods positioning was used most frequently. The emotional support offered consisted of comfort, touch and presence. Lack of workforce was a factor that limited the nurse's use of non-pharmacological methods.

### *The family as caregiver*

The concept of the relative as caregiver is of interest to this study and is presented based on previous research in the area. The transition to community-based care has increased the awareness of the extent and importance of family caregiving in keeping patients at home as long as possible, when suffering from a severe disease (Kitrungrote & Cohen, 2006). Family caregiving is included in the generic care described by Leininger (1991, 2002b, 2005a) and in the natural care described by Eriksson (1987).

The "family caregiver" is usually broadly defined as the immediate family, whilst the "professional caregiver" refers to an individual who has specialized knowledge or skills which he/ she applies in a paid profession, or in voluntary work (Haigler et al., 2004). The authors continue by claiming that the caregiver needs education and support to be able to conduct the care. When taking care of a patient with a severe disease or disability, the family caregiver is part of a triad consisting of the professional caregiver, the family caregiver and the care recipient. Today many family caregivers carry out tasks which were previously the responsibility of highly skilled and trained professional providers. These family caregivers consequently need support in conducting the care, and there is a need for new models concerning this support.

This idea of a "caregiving triad" can be seen in Bondas' (2000) study concerning women's experiences of pregnancy. She does not however discuss the relationship between the pregnant woman, the family (partner) and the professional nurse in terms of a triad. She emphasizes the importance of a caring relationship within the family during pregnancy, and links this to natural care. She points out the importance of professionals involving the family (in this case the partner) in the care of the pregnant woman during and after delivery. The family today has not always a natural place in the caring relationship during pregnancy and at delivery. The professional care needs to have elements of natural care; it is then experienced as caritative care. The concept of fam-

ily and how family is viewed is not described or discussed extensively enough within caring science, and needs to be further developed.

Berry (1999) described and analyzed the meanings, expressions, and experiences of generic and professional care during pregnancy among Mexican American women. She reports that generic care is essential for the women's wellbeing. Generic care is here described as protection of the care recipient and as an obligation of the caregiver. Family care filled the purpose of showing respect for the family. Bonura, Fender, Roesler and Pacquiao (2001) report similar findings among Jewish patients and describe caring as a communal obligation that gathers the family and community into a cohesive unit. Leuning, Small and van Dyk (2000, 2002) focus on generic care among elderly people and they describe generic care as nurturing the health of the family, trusting the benevolence of life as it is lived, honouring one's elders, and sustaining security and purpose for life. Dunst, Boyd, Trivette and Hamby (2002) suggest a family-centred model of empowerment, which views the family as capable of caring for their own members. The family here mobilizes the necessary resources and channels of support, as an alternative to the traditional models for caregiving, where the responsibility for caregiving decisions is placed on the professional caregivers. Wiles (2003) found that many family caregivers experience confusion concerning the formal support system: they see it as fragmented and as an arbitrary collection of service. He stresses the difficulty in finding one's role in the system, and how the family caregivers prefer to be seen as co-workers who get support in their caring role. Winslow (2003) also emphasizes the family caregiver's need for support within the health care system and Hogstel, Curry and Walker (2005/2006) find that the burdens and strains of family caregiving for the elderly are frequently reported in health-related literature, while the benefits are often ignored. The family caregivers experience benefits from taking care of older relatives when having the possibility to celebrate small things, and through this find a mutual source of joy. They can also resolve family pain and conflicts from the past, develop personal strength and prepare for the aging process. Taking care of an older relative also allows the caregiver to experience the older person's whole life – here and now, there and then.

## **Culturally competent care**

Cultural competence and culturally congruent care are the topic of several theorists and researchers under the transcultural nursing umbrella. The different topics will be described from different angles below. Cultural competence is a relatively new concept in nursing literature and culturally congruent care is a concept seldom used except by researchers in the transcultural tradition.

### *Cultural competence in caring*

Cultural competence is an important foundation when caring for people from another culture than your own. By using “culturally competent care” as a keyword, a huge amount of articles are found although it is a relatively new term in nursing publications, as it was first mentioned in 1989 (Buruchum, 2002).

The concept of cultural competence is described in several models and Buruchum (2002) has conducted a concept analysis<sup>15</sup>, following Rodgers evolutionary method of cultural competence. The analysis shows that in 1992 “ethnic competence” was used and this concept includes characteristics of the later concept “cultural competence”. The attributes which were found to describe cultural competence were cultural awareness, cultural knowledge, cultural understanding, cultural sensitivity and cultural interaction. The concept analysis showed that cultural competence refers to a process or a journey, which supports such as Purnell’s model described in Purnell and Paulanka (1998) as well as Campina-Bacote’s (2002) and Well’s (2000) description of cultural competence. Meleis (1999) defined culturally competent care as the acknowledgment of differences in advocacy for marginalized clients and intolerance of inequity and stereotyping, which shows the content of the concept in a slightly different way. Melis further mentioned marginalized clients and emphasize the differences in cultures.

Campina-Bacote developed a model called “The process of cultural competence in delivering healthcare services” in 1991. The model was renewed in 2002 and now (2007) has the shape of a volcano, where cultural desire is the force that spreads cultural awareness, cultural encounters, cultural knowledge and cultural skills. The Purnell Model for Cultural Competence (Purnell & Paulanka 1998; Purnell 2002) started as an organizing framework for student nurses to use as a clinical assessment tool. The model is applicable to all health care disciplines in all practice settings and it is classified as a complex and holographic model. It is based on several theories and a research base gained from several sciences and fields. The model views cultural competence as a development, not something static. The development of cultural competence happens through several phases: unconsciously incompetent -> consciously incompetent -> consciously competent -> unconsciously competent. The process is not linear, rather cultural competence develops by moving back and forth between the different stages.

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<sup>15</sup> Buruchum (2002) used Rodgers’ evolutionary method of concept analysis where the conceptual attributes formulates the meaning of a concept rather than definitors. The goal for this kind of analysis is to focus on the identification of attributes rather than the development of the concept. Burchum used about 30 author’s definitions and descriptions of cultural competence to form the presented attributes.

Papadopoulos, Tilki and Taylor (1998) developed a model for culturally competent health practitioners, which consists of four concepts: cultural awareness, cultural knowledge, cultural sensitivity and cultural competence. Lister (1999) developed taxonomy for cultural competence, and Koskinen (2003) in her research focused on education and designed a model for the development of cultural competence among students in nursing education.

There are several studies concerning cultural competence in nursing education. Scholes and Moore (2000) have developed a model which can increase the student's sensitivity towards cultural differences. A model for intercultural competence within nursing education is developed and reported in Koskinen and Tossavainen (2003a, 2003b) and Koskinen (2003). Parish (2003) discusses whether cultural competence should be a core competency in nursing education, and Chanales and Bowers (2000) discuss the lack of progress in teaching and evaluating cultural competence when focusing on a minority nurse educator group. Alpers and Zoucha (1996), Felder (1990), Kulwicki and Bolonik (1996), Rooda (1993), in their research focus on nursing students' and nursing faculties' attitudes and knowledge about culturally different people.

The ethical issue in caring for people from another culture than your own is what Hanssen (2002, 2004) deals with, when she describes nurses' encounters with patients from cultures other than their own. The encounters are characterized by the nurses "wanting to"<sup>16</sup> carry out culturally congruent care, but also by the difficulty of simply not understanding the caring needs of the patient. Hanssen puts forward how people from different cultures have different values and how nurses are concerned about treating the patients with respect and in an ethically correct way. Hanssen (2004) discusses the constitution of ethical nursing practice in intercultural nursing, and focuses mainly on the concept of autonomy and disclosure, through interviewing 23 Norwegian nurses at 12 different hospitals. She found that autonomy is an important value for nurses and discusses the ethical conflicts that might arise when patients and nurses do not share the same value of autonomy. Xu (2004) comments on the research results described above and claims that autonomy is not seen the same way in Chinese cultures as in Western cultures. From a Chinese perspective, the advocacy of one family member's total independence from the rest of the family is impossible and not culturally correct. "White lie" scenarios are not uncommon to Chinese physicians when it comes to a life-threatening diagnosis such as

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<sup>16</sup> Hanssen's (2002) findings can be compared to Campina-Bacote's (2002, 2007) model of cultural competence with the five main domains where "desire" is the force that creates knowledge, skill, awareness and a search for encounters. The desire as it is explained by Campina-Bacote is similar to Hanssen's findings when she explains the nurses "want to" do a culturally competent care.

terminal stage cancer. The physicians want to shield the patient from the potentially negative effects of overwhelmingly bad news. From the Chinese perspective, telling the truth may in this case hasten a negative health condition, and “white lies” are culturally acceptable. Both Hanssen (2004) and Xu (2004) agree that culture is to be taken into consideration when caring for people from a culture different than one’s own. The “white lie” is also discussed by Tuckett (2005), from another angle, and without a cultural perspective. Truth telling is important for patients, since it promotes trust and comfort in the relationship. Patients want honest and clear information; to tell the truth is to share information honestly and the intention of doing it correctly is important, it is one of the most important tasks expected from the nursing staff. However, nurses and doctors tend not to give bad news to the patient since it contravenes perceived duties of benevolence and nonmaleficence. Truth-telling might cause distress, anguish and depression.

### ***Culturally congruent care***

Culturally congruent care is closely linked to culturally competent care, a concept used by several authors. When searching databases with the keywords “culturally congruent care” few articles were found. Most articles used Leininger’s theory and model as the framework of their research, and the research was done with various themes and approaches. De Villiers and Tjale (2000) discuss maternity care in Africa, Elliott (1994) discusses Russian nurses’ experience of health care systems. Hubbert (2005) focuses on adults residing in homeless shelters based on Christian philosophy in urban Midwestern, and Chimelarczyk (1991) discusses how to provide culturally congruent care to the Hausa of Northwest Africa. Ito and Sharts-Hopko (2002) studied Japanese women’s experiences of childbirth in America, and found that the women identified areas of uncertainty and unfamiliarity that health care professionals should be aware of, in order to facilitate the negotiation of culturally congruent care. Zoucha and Husted (2000) discussed the ethical dimensions of carrying out culturally congruent nursing and health care. Malinowski, Stamlar and Leeseberg (2002) linked the ideas of “comfort” presented in literature to theories of Watson (Human Care) and Leininger (Culture Care) and found comfort to be an indispensable element of holistic, culturally congruent human care in the process of healing.

### **Summary of literature**

Suffering is a complex, subjective and negative experience, which is social since it occurs in the interplay with other people. Suffering can also be pri-

vate and hidden (consciously or unconsciously) from others. Suffering can be caused by illness, treatment, lack of nursing care, and due to a threat to human existence itself. The nurses' attitude can influence suffering. Caring can be life-giving and non-care can be life-destroying. Suffering can also occur due to social factors, such as politics, institutions, class or gender. The suffering experience can be described and understood by observing different phases. The different phases can be seen from a behavioural perspective which makes the phases of enduring and emotional suffering visible. Suffering can also be seen as a process, involving different phases that the sufferer needs to go through to achieve health. The different phases in the suffering experience prerequisite different ways of meeting the patient's caring needs. The patient needs to go through suffering in order to find reconciliation or a reformulated self. It is not only the patient that suffers; relatives and nurses suffer as well as they become part of the suffering experience.

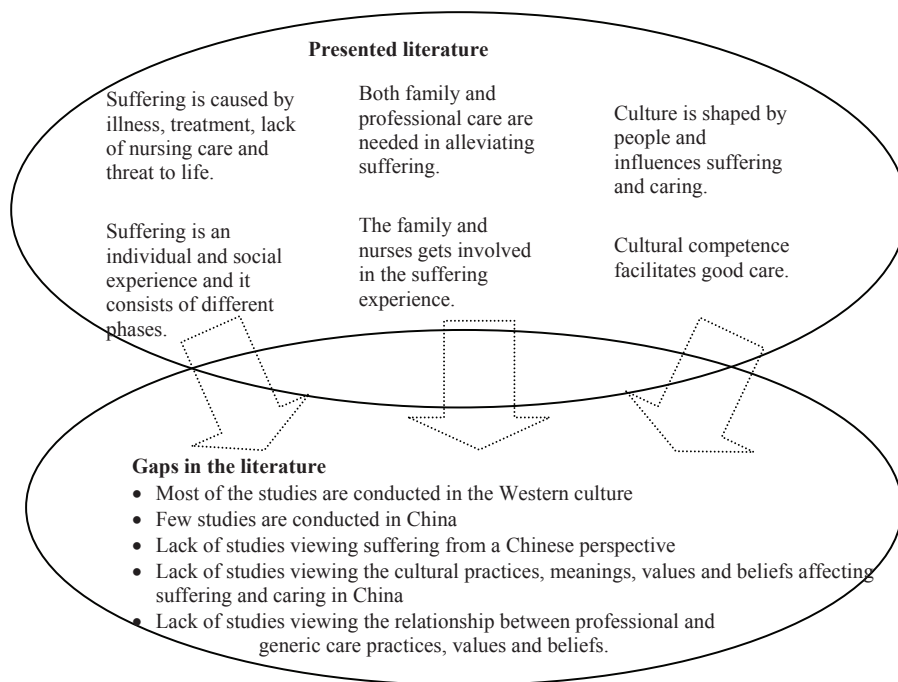
Suffering is the motive for caring and caring exists in a relationship. The sufferer is vulnerable and needs care to achieve health. The sufferer might hide his/her suffering from others. To find reconciliation the sufferer needs to be seen and confirmed in the suffering. Suffering and caring are expressed both verbally and non-verbally and the correct understanding of signs and messages is a prerequisite of good care. Suffering is social and can be relieved through communion in a caring relationship. The caring relationship can consist of interplay between the family caregiver and the patient, or between the patient and the nurse. Today there are deficiencies in the co-operation between family caregivers and professional caregivers, which negatively influences the patient's attainment of health. Suffering changes a person's social role and life, not only the sufferer's but also the nurse's and the family's social roles. Communicative actions involving information and education are important parts of professional care aiming at alleviating suffering.

Culture is shaped by people and culture influences the suffering expression. Pain, suffering and care differ cross-culturally. Culturally competent and congruent care is necessary to avoid cultural pain, cultural blindness and cultural imposition. Several models have been created aiming at increasing cultural competence in nursing. Attaining cultural competence prerequisites a desire for competence and results in cultural awareness, cultural encounters, cultural knowledge, cultural skills and cultural sensitivity. It is a process to become culturally competent. Cultural incompetence can cause cultural pain.

Figure 2 illustrates a summary, as well as gaps in existing literature. The gaps



in the literature cited illustrate the fact that research in this area has predominantly been carried out in Western culture and this demonstrates the necessity in conducting studies concerning suffering, care, caring and culture in other cultures than Western culture.



*Figure 2. Summary and gaps in existing literature about suffering, care, caring and culture care.*

## 4. Culture as a concept in caring science

Studies in caring science which combine care and caring with culture and cultural patterns are not common in Finland even though an increasing interest can be observed in this field in Finland as well as in other parts of the world. The chapter presented below is not vital to an understanding of the present study but nonetheless necessary in order to present the ongoing development of substantial and methodological knowledge in research in transcultural nursing and related fields. Studies conducted from the perspective of cultural similarities and differences aim to create knowledge about human beings in a cultural context. Transcultural nursing is currently included in an increasing number of books, textbooks and articles that are published in the field. The chapter starts with an overview of the definition of the concept “culture”.

### The definition of culture

In an ethnographic study, culture and cultural patterns are of interest. The United Nations Economic, Social and Cultural Organization, UNESCO (2001) emphasises the importance of every human being’s right to his/her own culture in the Universal Declaration on Cultural Diversity. The declaration includes that culture is at the heart of contemporary debates about identity, social cohesion, and the development of a knowledge-based economy. Tolerance, dialogue, cooperation and respect for the diversity of cultures create the best opportunities for peace. Respect for cultural diversity and the development of intercultural exchange is important, when considering that the process of globalization creates the conditions for renewed dialogue among cultures. Culture can consequently be said to be an important part of human life.

The definition of culture has changed over time. It is said to have been first described by Sir Edward Tylor, a British anthropologist, who defined culture as “the complex whole, including knowledge, belief, art, morals, law, custom and any other capabilities” (Andrews 1999; Helman 2001). Helman (2001, 2) describes culture as “*a set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally and how to behave in relation to other people, to supernatural forces or gods and to the natural environment.*” This description opens up for different descriptions and definitions depending on the starting point chosen.

The interest in combining culture with caring and nursing within nursing sci-

ence is first seen in literature written by Leininger<sup>17</sup>. The combination of the concepts “caring” and “culture” can be used in different ways and according to Wikberg and Eriksson (2003) a combination of the two concepts can be used when discussing “caring culture” at a ward, among staff groups and then describing the spirit, rules and strategies prevailing at a ward, hospital or among different groups. Culture in care can also be used when discussing music, dance, and drama in connection with care, used as forms of therapy. In this particular study culture is used with an ethnic focus, describing a specific context in a Chinese setting.

The discourse on culture carried out by the American anthropologist Hall<sup>18</sup> is often mentioned in literature. He is referred to as the founder of intercultural communication and states that communication constitutes the core of culture (Brown, 2006; Rogers, Hart & Miike, 2002). Hall (1984) views culture as existing on three different levels; the explicit manifest culture visible to the outsider (social rituals, traditions, national cuisine and festive occasions), the deeper levels only known to members of the cultural group itself and seldom shared by members outside the group (consisting of rules, norms and assumptions hidden from the outsider), and finally the deepest level of culture which is the primary level of culture, where the rules are known to all, and followed by all, but seldom ever stated (hidden from the outsider). These rules are implicit, taken for granted and almost impossible for the average person to state as a system.

Culture can be viewed either as dynamic or static, which is described by Kao, Hsu and Clark (2004). When culture is viewed from a static perspective, the focus lies on the concrete existence of a culture with rules and norms guiding behaviour in a group. This view tends to be supported by the positivism

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<sup>17</sup> Leininger was the first nurse-anthropologist to create a nursing theory (1978, 1991, 2005a) of which culture is one of the basic foundations, and her definition of culture has often been used in later nursing/caring research. Leininger's definition of culture has changed over time. In 1966 Leininger discussed the concept of culture based on Herskovit's definition and found that culture is a universal experience and cultures differ from each other. Later Leininger (1978) describes culture as “*learned and transmitted from one generation to another, largely through the enculturation and socialization practices of a designated group or culture*” and it is “*the shared and expected values and behaviour among a particular group of people which are dynamic, changing and diversified*”. In 1992 she defined culture as “*the learned, shared and transmitted values, beliefs, norms and life ways of a particular group that guides their thinking, decisions and actions in patterned ways*”, and later (1997a, 38) she defines culture as “*the life ways of an individual or group with references to values, beliefs, norms, patterns and practices that are learned, shared and transmitted inter-generationally*”. Generally Leininger's definition tends to be broader and not so detailed in later versions. Leininger's definition of care and caring will be further described in the theoretical perspective.

<sup>18</sup> Anthropologists generally focus on macro-level, single-culture studies but Edward T. Hall, Ph.D. in anthropology (is seen as one of the creators of modern anthropology) coined the term “intercultural communication” and is acknowledged to be the founder of the field. Hall focused on the micro-level behaviours of interaction between people of different cultures (Rogers et al., 2002).

which suggests that culture can be measured and predicted without entering into people's inner world. When looking at culture from a dynamic perspective it has no concrete reality and exists only in a person's mind.

When adopting a dynamic perspective on culture it can be seen as a cognitive system (Geertz, 2000a, 2000b). He describes that the cultural system shares symbols that are cumulative creations of human minds. Human beings ascribe meaning to experiences and thoughts, and culture becomes a model through which we act and react. The study of other people's culture involves discovering who they think they are and what they think they are doing. It also includes getting familiar with the frames of meaning within which they live and learning how, as a being from elsewhere with a world of one's own, to live with them.

Culture is in caring and nursing science described<sup>19</sup> as an integrated system of historically learned patterns of behaviour and ideas<sup>20</sup> (worldview or paradigm), which are public and have a meaning. They are passed from one generation to the other<sup>21</sup> (socially transmitted) and they are shared by a population or a group (and the culture influences the group's values, beliefs and behaviours, culture has to be seen in its context<sup>22</sup>). New patterns are created in social relations between participants in the situation (or in the group, institution<sup>23</sup>) - the culture is not static, but changing. Products<sup>24</sup> that are characteristic of a society (such as dress, food, arts, social institutions, language) are important manifestations of

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<sup>19</sup> Geertz and Mead are anthropologists and their works are not linked to caring science but are although used in this description of the concept "culture". Mead is one of the first female anthropologists publishing work important for later debate and development and Geertz is included because of the influence his writing has on the present study. Helman, who is a medical anthropologist, is also used in the description of the concept of culture.

<sup>20</sup> Mead enlarges the concept "culture" to include the system of technology, the political practices, and small intimate habits of daily life such as the ways of preparing and eating food, or of hushing a child to sleep (Yans-McLaughlin, 1988). Geertz (2000a) (ethnographic perspective) and Dahl (2004) (health care perspective) both define culture as a model that the individual has for actions and thoughts and this shapes patterns of meanings which Dahl refers to as codes in mind.

<sup>21</sup> Most of the descriptions of culture include a statement of culture as transmitted through generations such as Geertz (2000a), Gieger and Davidhizar (1999), Leininger (2002b, 2005a), Purnell and Paulanka (1998), Spector (2002).

<sup>22</sup> Geertz (2000a) says that culture is a context in which social events, behaviours, institutions or processes can be causally attributed, which is supported by Helman (2001) who says that the role of the culture has to be seen in its context. The context is made up of historical, social, economic, political and geographical elements and the culture of any group of people at any particular point in time is always influenced by many factors.

<sup>23</sup> Andrews (1999, 3) writes that "*culture represents a way of perceiving, behaving and evaluating the world. It provides a blueprint or guide for determining peoples values beliefs and practices including those pertaining to health and illness*". The world is rapidly changing and so is culture, new patterns are formed due to the evolution of society.

<sup>24</sup> Leininger (2002b, 2005a), Spector (2000), Purnell & Paulanka (1998), Gieger & Davidhizar (1999) include products of human work that are affected by internal and external stimuli and artistic manifestations as important parts of culture. Through the products we create symbols important for expressing our culture.

that society's culture. The concept is commonly seen as a pattern of symbols, meanings, premises and rules<sup>25</sup> and the purpose of investigating these patterns is to try to find meanings, to structure them and through this to understand the culture<sup>26</sup>.

## **Transcultural nursing theory generation and development**

The presentation is based on literature and the search has been limited to publications from 1995 to 2006 in CHINAL and EBSCO. Keywords used were *trans/inter/cross/multi cultural nursing/caring/care, ethnocare, and inter/trans/cross cultural nursing/caring relations/ nurse/patient, nursing and suffering, culture and trans/cross/inter/multi cultural nursing/caring/care, culturally congruent care, cultural competence, culture care, suffering and caring/nursing* and thousands of articles were found. The chapter begins with an overview of the history of transcultural nursing and is followed by a presentation of different perspectives such as cross-cultural, multicultural, international, intercultural nursing and caring aiming at creating new scientific knowledge.

Transcultural nursing is a relatively new research field within nursing science, and the research field needs theory development. A lack of congruence in usage of concepts is mentioned by Davidhizar, Bechtel and McEwen (1999), Duffy (2001) and Jansen (2006). Concepts are borrowed from different sciences (such as anthropology and social sciences) and research is sometimes done without any connection to a solid theoretical foundation for transcultural nursing. A great deal of literature has been published, but lack of rigour in references and the use of common knowledge as "facts" may mislead the reader (cf. Davidhizar, et al., 1999). The need for further research and development of substantive theory of transcultural nursing is necessary. Nevertheless, the existing research and publications have already contributed to a valuable knowledge of the health beliefs and practices of people from different cultural groups (Spence, 2001).

Andrews (2005) has described three historical periods in the development of transcultural nursing. In the 1940s and 1950s there were no formal, explicit or specific theories of nursing, but there were general ideas communicated

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<sup>25</sup> Newman (1998); Burchum (2002); Leininger (1991, 1997b, 2002b) Purnell & Paulanka (1998), Purnell (2002); Andrews (1999); Spector (2000).

<sup>26</sup> To grasp the meaning of an action Geertz (2000a) uses "thick descriptions" of a culture by answering the questions of what how and why the actors are acting. Culture is shaped by human beings and culture also shapes us as who we are and the meanings behind our actions.

by nurse leaders that were considered important in guiding nursing practices. During the first period (1955 – 1975) transcultural nursing was established for the advancement of nursing knowledge and practices. The claim that caring is the essence of nursing was a new idea as well as combining culture with care and caring. Leininger combined two scientific fields, namely anthropology and nursing and created the field of transcultural nursing as a formal area of study and practice. Leininger developed her theory of Culture Care Diversity and Universality during this period, and outlined a research method according to her theory (ethnonursing combining anthropological and nursing research<sup>27</sup>). In the second period (1975 – 1983) transcultural nursing gained global interest and education programs, research and development of nursing practices in transcultural nursing were established. The third period stretches from 1983 to the present date. The Journal of Transcultural Nursing was established during this period and an increasing amount of research within the field was done. In recent years the focus of the articles in this journal has increasingly reflected the transnational expansion of nursing. Other journals concerning transcultural nursing are published, such as Journal of Multicultural Nursing & Health and Journal of Cultural Diversity. During the last decade several workshops and conferences in transcultural nursing have been held in different parts of the world and there is a growing interest in developing substantial knowledge in this area.

The widespread acceptance of transcultural theory necessitated the entry of transcultural nursing as a subject heading in CHINAL in 1981 (Gustafson, 2005). De Saints (1994) points out that when the definition of transcultural nursing is broken into components, several aspects of making anthropology clinically relevant stand out: a nurse – patient negotiation model is inherent in transcultural nursing, a simultaneous dual ethnocentrism is operating, multiple cultural contexts and patients are cultural informants and the cultural dimension is inherent to the nature of nursing. De Saints describes transcultural nursing as the integration of the concept of culture into all aspects of nursing care.

The term transcultural nursing is sometimes used interchangeably with cross-

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<sup>27</sup> Ethnonursing refers to a “*qualitative nursing research method focused on naturalistic, open discovery and largely inductive (emic) modes to document, describe, explain, and interpret informants’ worldview, meanings, symbols and life experiences as they bear on actual or potential nursing care phenomena*” (Leininger, 2002b, 85). Polit and Hungler (1999, 701) describes ethnography as “*a branch of human inquiry, associated with sociology, that focuses on the culture of a group of people with an effort to understand the worldview of those under study*”. Leininger’s research method “Ethnonursing” has many similarities with ethnography (cf. Jansen, 2006), and the main difference is that ethnonursing focus on nursing. Leininger sees ethnonursing as a research method with different tools named “enablers” to facilitate the conduction of the study.

cultural, intercultural or multicultural nursing in literature. Searches in databases<sup>28</sup> showed that the term “intercultural” combined with “nursing” was not often used before year 2000 (5 references) and then it was used in a context concerning intercultural communication (Pfeifer, 1995) and education (Iwata, 1996; Nolde & Smillie, 1987). Kavanagh, Absalom, Beil and Schliessmann, (1999), DeSantis (1994), and DeSantis, Thomas and Sinnett (1999) use the concept “intercultural” but do not in detail define or discuss the usage of the term. Searches with keywords “intercultural” and “nursing” between 2000 and 2007 gave 31 hints<sup>29</sup>. The term “intercultural” and “nursing” is used after year 1999, among others by Alexis and Chambers (2003), Coler, and Coler, (2001), Fuller (2003), Hanssen (2002), Kirkham (2003), Koskinen (2003), Wikberg and Eriksson (2003). The term is not described, discussed or defined except by Hanssen (2002), Koskinen (2003) and Wikberg and Eriksson (2003). When combining “intercultural” with “caring” only 9 articles are found<sup>30</sup> and they mainly focus on caring in an intercultural environment (Davidhizar & Giger, 2004; Dundon, 2005; Orr, 1996) and nursing education (King 2004; Kosowski, Grams, Taylor & Wilson, 2001). The concept has been used in social sciences since 1960:s among others McOmie, (1990) and Banks and Banks (1995).

Transcultural nursing is criticised both as a research area and an arena for nursing care for example by Gustafson (2005), who discusses transcultural nursing theory from a critical cultural perspective. She claims that transcultural theory has two fundamental problems; firstly that it gives primacy to a broadly defined, but narrowly applied concept of culture and secondly that it emerges from a liberal and depoliticizing standpoint, which perpetuates rather than interrupts the dominant ways of interpreting and addressing human and social differences. Swendson (1996) discuss similar topics and argue that contemporary understandings of multiculturalism in nursing and health care policy tend to obscure, ignore and thus perpetuate notions of racial superiority. This perspective, given legitimacy in terms of cultural sensitivity, encourages political neutrality and thereby avoids questioning the discriminatory practices embedded in fundamental social relations.

The discussion concerning transcultural nursing includes both of the two paradigms of caring and nursing science, as well as the different meanings brought into the concept. Leininger (2005a) sees caring as the essence of (transcultural)

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<sup>28</sup> Academic Search Premier, Health Source: Nursing/Academic Edition, CINAHL 23.02.2007

<sup>29</sup> Academic Search Premier, Health Source: Nursing/Academic Edition, CINAHL 23.02.2007

<sup>30</sup> Academic Search Premier, Health Source: Nursing/Academic Edition, CINAHL 23.02.2007

nursing, which is defined as a discipline of study<sup>31</sup> and practice that focuses on differences and similarities among and between cultures in order to assist human beings to attain and maintain meaningful and therapeutic health care practices that are culturally based. Eriksson and Wikberg see all nursing as including the cultural issues (2003) and assert that no specific transcultural model is needed. It is suggested that the term “intercultural” would be used instead of transcultural when discussing issues concerning caring and culture.

However, transcultural nursing is used worldwide as a description of a special area dealing with issues of culture and care. The usage of the concept “transcultural nursing” placed the research field within nursing research and nursing science. The fundamental issue in transcultural nursing is however “caring as the essence of nursing”. The research done in transcultural nursing consequently often concerns non-professional caring (generic care) and can also be linked to the research done within caring science, since it is not directed exclusively to the professional nursing, it is directed to the caring for people.

### ***Cross-cultural studies***

The word “cross-cultural” comes from cases in anthropological research in which cultural groups have been compared to each other. A cross-cultural study will consequently look for phenomena which occur within a culture or group and then one can search for contrasts and similarities and compare these with other cultures. When discussing “cross-cultural” as a concept, Kluckhohn should be mentioned. Kluckhohn was a Harvard sociologist and anthropologist in the first half of the twentieth century (1905-1960), who advocated “cross-cultural values”, values that all cultures have in common (Corey 1999). Brink (1999) also sees “cross-cultural” as comparing cultures but with a focus on diversities. This approach is supported by anthropological research (cf. Spradley, 1979). Several articles are found when using “cross-cultural” and “nursing” as keywords. Most of the articles such as Bushy (2002) Degeling, Hill, Kennedy, Coyle and Maxwell, (2000) Lobra, Youngblut and Brooten (2006), Richter, Eisemann, Bauer, Kreibeck and Åström (2002), Watson, Deary, Hoogbruin, Vermeijden, Rumeu, Beunza, Barbarin, MacDonald, and McCready (2003) compare various nursing issues in different cultures and countries, and the research is done in form of joint projects involving participants from many different countries.

Another topic which is frequently mentioned in this area is the cross-cultural

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<sup>31</sup> A discipline of study is in this study understood as similar to a research area, not as a science of its own. Transcultural nursing can be seen as a research area within caring/nursing science or as clinical nursing care.



development of different measurement tools that can be used globally and also the cross-cultural testing of different tools. The following articles presented are examples of these topics. Kara, van der Bijl, Shortridge-Baggett, Asti and Erguney (2006) aimed at adapting a Dutch/English version of the diabetes management self-efficacy (SE) scale for use within the Turkish population and at evaluating its psychometric properties. Wen-Ling, Hwei-Ling and Fetzer (2006) describe a five-step translation procedure as well as an equivalence and reliability testing process used to develop the “High School Questionnaire; Profile of Experiences (HSQ)” in Mandarin. Hsueh, Phillips, Cheng; Picot and Sandra (2005) present a study in which Picot’s caregiver rewards-scale (PCRS), originally developed in English, was cross-culturally validated with 137 Chinese adult children as family caregivers in the United States. Results suggest that the Chinese PCRS is a summative measure of perceived caregiver rewards with the potential of evaluating interventions to reduce perceived burden among adult children families.

Spence (2001) has a different approach in her study. She discusses how to use hermeneutics as a research method to extend the understanding of cross-cultural nursing practice. She focuses on the term “prejudice” and the various “plays” inherent in nursing practice. She finds hermeneutics as to be useful way to increase substantial knowledge about cross-cultural phenomena.

### ***Multicultural studies and ethnocare***

The term multicultural is used in a similar way to the term transcultural (Rooda 1992, 1993), and several articles are found in this area<sup>32</sup>. Most of the articles are written between 2000 and 2007. When searching for “multicultural” and “caring” 53 articles are found. Multicultural is used when discussing several cultures, differences and diversities in cultures, as well as when discussing nursing or patient education (Cutilli 2006; Malu 1994; Smith 1993; Pinikhana, 2003). Allen (2006) argues that representations of ‘multiculturalism’ within nursing need to be based on a theory of whiteness, a historicized understanding of how ethnic/cultural differences come to be represented in the ways they are informed by Foucault’s notions of power/knowledge. By using nursing education and “cultural competence” as examples, the study draws on a range of literature to suggest more critically and politically productive ways of approaching difference from within nursing’s largely white interpretive framework. Campina-Bacote (1998, 2003) uses the word multicultural to describe our diverse societies and diverse caring needs.

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<sup>32</sup> 233 articles in Academic Search Premier, Health Source: Nursing/Academic Edition, CINAHL 23.02.07.

Critics have suggested that the focus on multiculturalism increases the distance between cultures and instead of opening up for a deeper understanding for the suffering human's need for care, it increases the distance between the nurse and the patient, a possibility especially criticized in nursing education (Duffy, 2001). Nevertheless other studies (Cortis, 2000; Davidhizar & Gieger, 2004; Orr, 1996; Xu, 2004) and theorists, under the "trans/inter/cross cultural umbrella" claim that caring for patients in a multicultural setting requires a perspective where the differences are outlined in order to help the nurse carry out good quality care.

Ethnocare<sup>33</sup>, as a concept, is used by Leininger (1984) and by Andrews (2005). Andrews uses the concept "ethnocare studies" describing studies within transcultural nursing. Ethnocare is also used by among others Orque, Bloch and Monrroy (1983) and it is defined as the nurse's integration of the patient's cultural background into nursing care or as describing the diverse cultural backgrounds of the patients. Ethnocaring as a concept is used by Eriksson (2001) referring to the innate non-professional care. Caring and nursing science concerning the trans-, inter-, cross-cultural topic seem to be in a creative stage and we need further discussion in order to define the different concepts, roles and modes that this area has in caring and nursing science.

### ***Transcultural models analysing the patient's culture***

Several models are developed for analysing the patient's culture and his/her specific nursing care needs when taking the culture into consideration. Leininger has, as a part of her theory Culture care Diversity and Universality, developed a model named "Sunrise model" which focuses on the specific worldview and the cultural and social structure dimensions of the patient, family or group. Based on the cultural and social structure dimensions, care can be given according to three different modes; Culture Care Preservation/Maintenance, Culture Care Accommodation/Negotiation, Culture Care Repatterning/Restructuring. The care is both generic and professional and, through a culturally congruent care, health increases. There is accordingly less possibilities for racism, ethnocentrism, cultural imposition, cultural blindness and cultural pain (Leininger, 1991, 1998, 2002a).

A model for ethnical nursing care has been developed by Orque and is presented in Orque et al. (1983). The model is system oriented and describes the

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<sup>33</sup> Ethnocare is not commonly used by researchers; only 4 relevant hints (concerning caring or nursing) are found between 1995–2007 in Academic Search Premier, Health Source: Nursing/Academic Edition, CINAHL 23.02.07.

human being as consisting of systems where culture is one system which is related to the biological, social and psychological systems. Giger and Davidhizar (1999) developed a model named “Transcultural Assessment model” in 1988 to respond to the need expressed by nursing students in an undergraduate program to be able to assess and provide care for patients that were culturally diverse. The model postulates that each individual is culturally unique and should be assessed according to six cultural phenomena; communication, space, social organization, time, environmental health and biological variations. The model is used in several studies where the aim has been to describe diverse cultures.

Several models show the development of cultural competence, and only a few of the existing models are presented here. Wells (2000) discusses the cognitive and affective phases in cultural competence based on a model named “Cultural development model” where the development is based on a movement from cultural incompetence through cultural knowledge, cultural awareness, cultural sensitivity, and cultural competence to cultural proficiency. The three phases which are mentioned first belong to the cognitive phase and the three later to the affective phase. Campina-Bacote in 1998 (edited 2003, 2007) developed a model called “The process of cultural competence in delivering healthcare services” which is presented in the chapter “Earlier research”. The Purnell Model for Cultural Competence (1998, 2002) is according to the author applicable to all health care disciplines in all practice settings and it is classified as a complex and holographic model. It is based on several theories and a research base gained from several sciences and areas.

## **Transcultural nursing research in Finland**

Few studies have been published within the transcultural nursing tradition in Finland. Meriläinen (1986) used ethnography as research method when studying different nursing methods in Finland. Hassinen-Ali-Azzani (2002) concentrated on Somali people’s health care beliefs and traditions when moving to a new country as well as how these traditions are perceived and practiced in Finland, and Juntunen (2001) investigated professional and lay care in Tanzania partly following Leininger’s transcultural model. Cultural competence was Koskinen’s focus in her doctoral dissertation (2003) and she has developed a model describing the development of cultural competence among exchange students.

Jansen (2006) discussed the philosophy of anthropology and how ethnography is used in nursing science in her doctoral dissertation. She found that there is

no general definition of ethnography; several philosophical, theoretical and epistemological perspectives were used. The author found that the philosophical foundation of ethnography lies in philosophical anthropology and that ethnography is often used in nursing research without discussing its foundations.

Several studies have nonetheless been conducted within the cross-cultural tradition with Finnish participants. The main part of the studies concerns nursing education, and the development of cultural competence. The cross-cultural approach is dominating and is seen for example in Dijkstra, Coleman, Tomas, Välimäki and Dassen (2003) where the aim of the study was to compare the psychometric properties of the Care Dependency Scale (CDS) internationally by analysing data gathered in Finland, Spain and the United Kingdom (UK). One of the main outcomes of the international comparison was that the findings between the three countries showed more similarities than differences in psychometric assessment, indicating that the CDS can be used for care dependency assessment in different countries. Friedmann, Åstedt-Kurki and Paavilainen (2003) discuss the challenges associated with the transfer of a family assessment instrument developed in the USA and its theoretical basis to a Finnish context. Vehviläinen-Julkunen (1994) compares the childbirth experiences of Finnish Lutheran women and compares the experiences to those of Canadian and American women. Heikkilä and Ekman (2000) investigates Finnish immigrants in Sweden and explores the role ethnic background plays in experiences and beliefs in elderly care.

Several articles concern nursing education, and the development of cultural competence. Below just a few articles are presented. Koskinen and Tossavainen (2003a, 2003b) focus on the development of cultural competency among exchanges students and Huittinen and Koskinen (2001) focus on the promotion of cultural learning in nursing education by utilising community nursing methods. Kennell, Ingalsbe and Nyback (2005) present an innovative educational project aiming to increase cultural knowledge by joint project learnt through a web-based course.

## 5. Chinese worldview – cultural and social structure dimensions

The aim of introducing the worldview<sup>34</sup> of The Peoples' Republic of China (PCR) including cultural and social structure dimensions is to form a framework for understanding the major tenets of Chinese culture in order to better understand and interpret the results of the study's data collection and analysis. The aim is not to give a full description of Chinese culture, but to increase understanding of the values and beliefs that underpin the culture at a basic level. The presentation has borrowed its structure from the Sunrise model created by Leininger (2002b, 2005a). The worldview of China and its cultural and social structure dimensions consist, according to Leininger (2002b, 2005a), of technological factors, religious and philosophical factors, kinship and social factors, political and legal factors, economic factors, educational factors, cultural values, beliefs and lifeways. These social structure dimensions influence care expressions, patterns and practices according to a holistic cultural perspective on health, illness and death.

The literature used is mainly based on earlier research and the databases EBSCO and CHINAL have been used. The literature search was conducted over an extended period (2000 – 2007). *China* and *nursing* in combination with *religion*, *cultural values*, *kinship*, *health*, *caring*, *nursing education*, and *technology* have been used as keywords. Literature concerning Hong Kong and Taiwan was mainly excluded, whenever used it is cited in the text. Information about political development and status, art, music, literature and geography was regarded as unnecessary for interpreting and understanding the research results and has been excluded. Literature not classified as scientific research was also used to some extent, for example Jakobsson (2001) who has described how it is to be a foreigner in China, Björkstrand (1988) who has written a textbook used in schools about different religions and diverse outlooks on life, facts from the National Bureau of Statistics (The People's Republic of China) as well as personal communication and daily newspapers. The text is illustrated by photographs, which is common in ethnographic publications. The photographs are not analysed, they are only used for illustrating the text.

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<sup>34</sup> Worldview refers to the way people tend to look out upon their world or their universe to form a picture or value stance about life or the world around them (Leininger, 1991, 2002b, 2005a) Worldview provides a broad perspective of one's orientation to life, people or groups that influence care or caring, responses and decisions (Leininger, 2005a).

The Cultural Revolution in China<sup>35</sup> has influenced all structural dimensions. During the Cultural Revolution the “intellectual class society” was forced to work in rural areas and the universities were closed. This process is called the reduction process and it affected the social system for a long period. There is a lost generation who did not have any opportunity to study at university, since Chinese people who are over 28 years are denied admission to college (Finn & Lee, 1996). The political developments are not further discussed in the paragraph presented below.

Statistics<sup>36</sup> show that China, with its population of 1,3 billion, or about 22% of the world's total population, is the most populous country in the world. In order to raise people's living standard the Chinese government, while focusing on economic development, began to implement its family planning programs in the early 1970s. In the early 1980s PRC set family planning, population control and upgrading population quality as a fundamental state policy. Now the family planning policy has continued for more than 20 years, and family planning has gained remarkable influence. Statistics from the commission show that China's population has been brought under control in the past 5 years, with the birth rate and natural growth rate dropped from 14.03 per thousand to 12.29 per thousand and 7.58 per thousand to 5.87 per thousand respectively.

## **Values and traditions**

Values and traditions are important keys to a culture and in the present study only a brief description of the values and traditions of China will be presented and contrasted to Western values. The comparison only involves general ideas. In every culture every individual has his/her own voice, values and view of the world, and these cannot be generalized. Similar trends and characteristics can nevertheless be seen in similar cultures. Culture is always in a constant state of change, it is not static. Values, guidelines for actions, behavioral, time and ethical orientation are influenced by the world outside the culture and therefore develop and change. Therefore the description of values influencing actions can only show a picture of what it is like now, not what it will be in the future. Below, in table 1, a comparison between Eastern and Western cultures is pre-

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<sup>35</sup> During the Maoist period China struggled hard to develop a new brand of socialism that would overcome old class cleavages and prevent new ones, which provided theoretical and practical innovations, some notable successes and several disasters (Blecher, 1997). Among the disasters the education system can be included.

<sup>36</sup> The bureau mentioned is The National Bureau of Statistics in The People's Republic of China and the publication in which statistics are found is China Population Information and Research Centre which is the leading unit of the China Population Information Network.

sented. The presentation only gives general ideas and cannot be said to be true for all individuals in a culture.

	<b>West</b>	<b>East</b>
<b>Values</b>	Focus on the individual Directed towards democracy Nuclear family structure Focus on young people Independence Self-assertion Avoid uniformity Competition Conflict Freedom	Focus on interpersonal relations Directed towards authority Extended family structure Focus on adulthood Mutual dependence Uniformity Co-operation Harmony Safety
<b>Guideline for action</b>	To satisfy individual needs Individual responsibility	Achieve common goals Common responsibility
<b>Behavioral orientation</b>	Express feelings Unique individuals	Control feelings Uniformity
<b>Time orientation</b>	Future oriented Innovation	Traditions Conservatism
<b>Ethical orientation</b>	The moral is anchored in the individual	The moral is shown in interpersonal relations

*Table 1. A comparison between Eastern and Western culture based on Hanssen (1998)*

Table 1 above shows the different orientations and priorities people in Eastern and Western cultures hold important. The table is a generalization and can only be used as a guide when learning to know the general features of a culture through comparison of cultural values, guidelines for actions, behavioral orientation, time orientation and ethical orientation. The cultures are changing and due to the globalization the differences are less obvious, at least at places where internet and exchange with other countries and cultures are common.

Western cultures are focused on the individual, contemporary society and

young people. Independence, individuality, competition and freedom are part of Western values (Hanssen, 1998). Eastern cultures are focused on interpersonal relations, mutual dependence and uniformity. Co-operation, harmony and safety are important and the focus is more on adulthood (Hanssen, 1998; Hsiao et al., 2005; Liu, Mok & Wong, 2006). These trends can also be seen in the ethical orientation of the cultures.

Kao, Reeder, Hsu and Cheng (2006) link the view of the human being in Chinese culture to the philosophies underpinning the values that dominate Chinese worldview. Confucianism emphasizes the significance of a social being by explaining that a person cannot exist alone and can learn and develop only in interpersonal connection within a social network. The Chinese have the word “Yuan” which means relationship and this word can be linked to how an ethical relationship is viewed according to Confucianism.

In Western cultures the main focus is on satisfying the individuals’ own needs and on one’s own responsibility to satisfy these needs, whereas Eastern cultures are more interested in common goals and the achievement of these. In a Chinese setting, according to Hsiao et al. (2005) and Kao et al. (2006) a person is viewed as a being in a social relationship and how this person acts for the benefit of the social relationship - society becomes a personal entity which is placed above any single individual. Beliefs and values related to family are as strong as religious beliefs for the Chinese. The family is more important than the individual. This is seen in how a person in a Chinese family is addressed. The family members seldom use the given name, instead they use the word explaining the relationship, like big sister (Jie Jie) or big brother (Ge Ge) or older sister-in-law (Sao Sao or older brother-in-law (Jie Fu). These titles are especially used when talking to a person older than oneself (Jakobsson 2001; He, personal communication 01.09.07).

In Western cultures it is acceptable to show feelings, whereas a person from an Eastern culture prefers not to show feelings, since it can be interpreted as “loosing face”. Western cultures are future oriented and focused on innovation, whilst Eastern cultures emphasize traditions and conservatism. There are several characteristics of the Eastern culture that can be related to socio-psychological factors. Social sensitivity is one of them and this includes not openly expressing interpersonal conflict. Conflicts are avoided because they disturb the harmony between person and environment or among people. Chen (1996, 2001) describes this element in the Chinese culture regarding relationship to authority figures. Doctors are still seen as authorities and experts, and challenging an expert is not proper in Chinese culture. If a patient mistrusts a doc-



tor, he will not openly express his concern, instead, he will simply not follow the instructions.

## **Religious and philosophical factors concerning health and suffering**

The Peoples' Republic of China is a multi-religious country including religions and philosophies such as Confucianism, Buddhism, Taoism, Islam, Catholicism and Protestantism. Acknowledging the wisdom of Chinese proverbs, most anthologies of Chinese religion are organized according to the logic of the three teachings (sanjiao) of Confucianism, Taoism, and Buddhism (Lopez, 1996). Daoism is another way of addressing Taoism. These old philosophies/religions still influence the philosophy of Chinese society. Buddhism appears to be a member of the same class as Confucianism and Taoism: the three teachings are "Rujiao" (teaching of the scholars or Confucianism), "Daojiao" (teaching of the Dao or Taoism), and "Fojiao" (teaching of the Buddha or Buddhism) (Lopez, 1996).

Based on information by the Central Peoples' Government of Peoples' Republic of China (2007) (white papers 2004, 2005), citizens may freely choose and express their religious beliefs, and make their religious affiliations clear. Although it is stated that the inhabitants of the PRC can freely express their religious beliefs, daily newspapers and news reveal to the world that minority movements which are linked to religious beliefs meet great difficulty in China<sup>37</sup>. According to Kao, et al. (2006) Confucianism and Taoism are the major belief systems of the Chinese people and they are inherently relational.

Confucianism is viewed as a philosophy of humanity and a guide to living. The founder of Confucianism is Kung-fu-tse (551-479), whose Chinese name was Kong Qiu, and who lived from 551 to 479 B.C.E. He was mainly a teacher of morals; the right way of living. The most important question in life was according to Kung-fu-tse "when heaven has given me this life – how shall I then live it the right way?" Confucianism advocates a reform of the government and governmental officials to work for the benefit of people, and cultivate virtue. It encourages respect for elders, legitimate authority figures, traditional beliefs, ritual practices, for education, and for close family bonds (Björkstrand, 1988; Lopez, 1996).

Confucianism has existed in China for several thousand years, which has in-

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<sup>37</sup> Amnesty International (2005) and Human Rights Watch (2003) report limitations in expression of religious beliefs in China.

fluenced the history of China as well as the Chinese way of thinking and acting (Blecher, 1997). Confucianism is the basic value system in China and Kung-fu-tse strongly believed in the goodness of the human being. It also stresses the promotion and restoration of ethical governments in order to promote individual regulation of behaviour, morals and success. In Confucianism the basic virtues of “Li” (proper conduct or respect), “Yi” (righteousness or morality), “Lian” (honest and clean), “Chi” (sense of shame), “Ren” (benevolence and humanism), “Ai” (love), “Zhong” (loyalty) and “Xiao” (filial piety) are important. Confucianism has been used as a protector of the strong family, which was seen as a threat during the revolution, but the idea of the strong family structure managed to survive (Björkstrand, 1988; He, personal communication 01.09.07; Leininger, 1995; Lopez, 1996).

Taoism means that human beings should be in harmony with the nature, which can mean to be outdoors. Chinese elderly believe that being in nature gives peace of mind. They also believe that deep breathing will promote health. In order to achieve health, an individual must modify him or herself to fit the natural rhythms of the universe. At the end of your life on earth, the Chinese perceive death as something natural and as an extension of life. Home is a place where people can feel safe and have a sense of belonging; therefore Chinese patients with terminal cancer usually wish to die at home. In dying at home, the Chinese retain a sense of normality (Chen, 2001).

Taoism can be dated back to the time between 280 and 240 B.C. The founder of the religion is unclear, but is thought to be Lao Tzu. Taoism is a philosophy and a worldview (also addressed as a religion by Lopez 1996) that promotes inner strength, spontaneity, selflessness, balance and harmony with nature and human beings. One belief and tradition originating from Taoism is the idea of Yin and Yang. Dao is the whole of Yin and Yang and the law of heaven and earth (Kao et al., 2006). Yin and Yang are essential in Traditional Chinese Medicine and health is viewed as harmony between the forces of Yin and Yang in the body as well as between the body and its environment. Illness is seen as the opposite of this harmony and therefore the imbalance or disequilibrium of Yin and Yang. Qi is the source of life and the energy that circulates in the body. In Traditional Chinese Medicine physicians focus on interruptions and blockages of Qi and this is seen as the driving force of the cosmos and human life (Chen 2001; Tsai, J., 2006).

Below is a photograph showing the symbol of Yin and Yang. It is taken outside the main entrance of the Fujian University of Traditional Chinese Medicine in China. The photograph shows the influence of the dark feminine power on the

light male power. Yin is the feminine power, characterized by darkness, passivity and cold. Yang is the masculine power, characterized by light, activity and heat. Together they make up Qi and, when in equilibrium they govern a person's moral and physical health. When reality is in balance and there is harmony between Yin and Yang people's ways of thinking and acting are influenced. Harmony, and lack of harmony influence the treatment and care given at hospitals; the patients' way of maintaining and regaining health, as well as their view of illness, suffering and life/death (Tsai, J., 2006). According to both Confucianism and Taoism a person is a holistic being with responsibilities. A person is viewed as an energetic system in the universe.

Another major religion in China is Buddhism. Buddhism began to enter China as the religion of non-Chinese merchants in the later years of the Han dynasty,

and the religion has spread from the southwest borders over the country (Lopez, 2006). Mercy, thriftiness and humility are the three treasures of Buddhism. "Yin" and "Guo" (which mean cause and effect) are the principles that encourage people to do well and do right and to receive good in return. "Yuan" (predestined relationship), "Yin" and "Guo" are the main factors that determine health. When people are aware of their behavior and are morally good, they have little or no guilt and are peaceful which promotes good health (Chen, 2001; He, personal communication 01.09.07).



*Photograph 1. The symbol of Yin and Yang outside FUTCM in Fuzhou. (Nyback, 10.08.2005)*



*Photograph 2. Buddhist temple in Fuzhou. (Nyback, 11.08.2005)*



*Photograph 3 and 4. Statues of Buddha in the temple area in Fuzhou. (Nyback 11.08.2005)*

Above some photographs of the Buddhist temple area at Gushan mountain in Fuzhou are shown. The temple area is old and a huge amount of visitors daily.

Yongquan Temple is located at the foot of the White Cloud Peak of Gushan Mountain, 455 m. above sea level. It is built in the Five Dynasties. As an ancient Buddhist temple on a famous mountain, it is the location of many places worth visiting. The photo above shows one temple in the big temple area. The temple area consists of several buildings and several statues of Buddha can be seen

Visitors can pray and wish for a better future, health, money, to give birth to a son or other important things they want to happen in their life. The picture to the right shows two statues of children, a boy and a girl, and the visitors can pray for a boy or a girl, and commonly the boy statue is more visited. Young and old people as well as families can be seen walking in the temple area.



*Photograph 5. Candles and the fragrance of incense at the temple place in Fuzhou. (Nyback, 11.08.2005)*

When visiting the temple candles can be lit and the fragrance of incense fills the whole area. Incense symbolises the fragrance of pure moral conduct and is a reminder to cultivate good conduct. When offering incense, people should examine their motivation and if they have any specific requests, such as prayers for longevity or the removal of obstacles to religious practice, they should be made at this point.



*Photography 6 and 7. Words of wisdom at the rocks and the path to the temple area in Fuzhou. (Nyback, 11.08.2005)*

The photograph shows a path at the temple area at Gushan mountain, and on several stones and rocks along the path monks and other wise people have written words of wisdom for people to reflect on when walking up to the temple. The signs on the rock are on some places big, which is seen on phtograph 6.



## **Cultural values and beliefs concerning caring, suffering and health**

Existing values concerning health and suffering have their starting point in ancient China and related to caring as well as health and suffering. The Chinese people's health and health-related attitudes are influenced by their cultural values, and the philosophy and religion that undergird these values. The teachings of Confucius principles for social interaction have a great influence on Chinese health behaviour according to Chen (2001). Chinese people do not generally

insist on asking why they have an illness, the foundation to the transition of accepting the illness can be found in the old religions and philosophies. "To let go" is derived from Buddhism and Taoism. Buddhism asserts that holding on to relationships, possessions and wealth is the source of pain and suffering ("ku"). "Letting go" helps to resolve the suffering. Similarly Taoism advocates "wuwei" which means dealing with things as they are and not as one would like them to be (Mok & Tam, 2001). Suffering is a part of life and it cannot be fled from (Mok, 2001). Mok continues and report base on her study that suffering has to be accepted ("Ting Tian You Ming" which can be explained as "follow as heaven guides"). "Wu Wei" and the fact that people understand their lack of absolute control over the world helps patients in accepting misfortunes, disabilities and limitations in their lives. Power comes from harmony with the universe. Patients also emphasize self-reliance ("Kao Zi Ji"). Due to some aspects of the Chinese cultural belief, the concept of harmony with the universe and "Wu Wei" enhances the patient's possibilities of accepting his/her illness and suffering as a part of life. This is also verified by He (personal communication 01.09. 2007). Harmony with all others, lack of self-centredness, respect for parents and loyalty towards the family are the main teachings of Confucianism (Chen, 2001).

In a Western tradition the patient's autonomy is endorsed by relying on a person's moral faculties of rationality and self-consciousness, but in a Confucian tradition, when a doctor approaches his patient, the patient is not only seen as a person whose autonomy and dignity are to be respected, but also a relational being with a family, a community and a social-historical context - a small self, encompassed by one or many greater selves (Tsai, D., 2006). Further Tsai continues by describing the family role, and in a traditional Confucian context the family means more than the individual, and it is considered as the basic unit. Doctors tend to seek the opinions and decisions made or agreed by the family as a whole. This is because of the emphasis on family values (wu-lun), the role family takes in caring for the sick, and the interconnectedness and interdependence between family members.

Based on Taoism, health consists of dynamic mechanisms in the flow of Qi, and in the tension between Yin and Yang as well as the five elements (metal wood, water, fire and earth which are the basic components of nature) (Kao et al., 2006). The Chinese believe in and seek a satisfying social life, happiness and peace to promote health and prevent illness. Taoism teaches that human beings should be in harmony with nature, which is seen when elderly people seek to promote their health by exercising outdoors. Nature gives peace of mind, and taking deep breaths of fresh air promotes health (Chen, 1996, 2001).

Chan and Palley (2005) describe breathing exercises as a way of “blowing away” emotional frustration. This technique is used by social workers in Hong Kong in the rehabilitation of elderly Chinese people.

According to Wong and Pang (2000) in Chinese tradition harmony and balance constitute the optimal state of being, but life is dynamic and harmony is not always present. Health promotion includes upright behaviour, taking care of oneself, keeping knowledge current, respecting and loving ones adult children and assisting with household and family tasks (Chen, 2001). A person’s health changes constantly. Illness is perceived as a state of disharmony between the individual and his/her natural and social environment in the Chinese tradition and harmony needs to be restored through curative and caring processes. Medical remedies help to restore the sick person to a balanced state, but the restoration of harmony is only made possible through suitable care.

To the right is a photograph showing people practicing a form of Tai Chi in a park in Fuzhou. This is a common sight in Fuzhou’s parks in the morning time and is seen as preventive health care, to promote qi.



*Photograph 6. People practicing Tai Chi in the morning light in a park in central Fuzhou. (Nyback, 13.08.2005)*

The concept nursing is in Chinese “Hu-Li”, which means protection and management (Kao et al., 2006). Caring behaviours have existed in China for thousands of years but the concept of nursing is new according to Wong and Pang (2000). The authors report that caring for the sick was seen as much more than conducting a collection of tasks that could be accomplished by servants. Caring still carries a strong notion of responsibility and moral duty. This follows the traditional way of viewing the family in China, but it also follows a holistic model of care.

Pang (1998a, 1998b) has investigated the moral experience of hospital nurses in the PRC and found that the nurses could outline five difficult care situations which commonly occurred in nursing practice. The five situations were:



disclosing information to patients, handling patients' or families' demanding requests, requests for euthanasia, inability to pay hospital fees and mismanagement of patient care. Mok (2001) investigated empowerment of Chinese cancer patients in Hong Kong from a Chinese perspective and found that the major themes revolving around the concept of empowerment included connectedness, partnership with health care professionals, reinterpretation of the illness and self-reliance. The participants in the study expressed that their power came from connection with people and from how their partnership with family and friends gave support. Health professionals were also considered to be important resources. In becoming empowered the participants were nevertheless also reconstructing their beliefs about the world. The participants in the study expressed that they had to accept the illness because it is a part of life. The acceptance of illness is enhanced by the traditional Chinese cultural beliefs about harmony with the universe, as well as "Wu Wei" and "Ting Tian You Ming". Similar findings can be seen in Mok and Tam (2000) in their study concerning coping methods among Chinese patients. They found that cultural beliefs influenced how Chinese patients viewed illness. People should not be afraid of suffering but should accept it. Practicing acceptance gives a person peace in the midst of uncertainty. People have no absolute control over the world nor the ability to change its course and this helps individuals to accept misfortune and limitations in their lives. How we feel and act depends on how we think and how we think results in how we feel and behave.

### **Technological factors affecting health and suffering**

Technological factors concerning health and suffering are closely linked to the value of education and development in the Chinese culture. The Chinese value education (Chen, 2001) and respect and honour the authority of a teacher. Wisdom is an important virtue in the Chinese culture, and elderly people are seen as wise people. From an early age, children are taught to have respect for learning and for acquiring knowledge, wisdom and the love of learning. Parents actively support their children and make substantial sacrifice, in order for them to get a sound education. The children in turn fulfil their responsibility which is an obligation to care for their parents and family throughout their lives (Leininger, 1995). The reduction process, during the Cultural Revolution, also obstructed the development of technology in medical science, since it obstructed the education of doctors and nurses.

The photograph below shows the high technology which is available on hospitals. A picture from the same information brochure is used as a background for the research design. Technological development is seen both at Universities

and hospitals linked to Western Medicine and to Traditional Chinese Medicine. At the Traditional Chinese Medicine Universities, research is conducted to develop the specialities within this specific area. When guided at hospitals, the new technology is naturally one of the most important areas to show; the newly equipped clinics with the latest technology for diagnostics, surgery and treatment.



*Photograph 9. The Intensive Care Unit, photo from the information brochure of affiliated Union Hospital of Fujian Medical University (2005).*

### **Kinship, family and social factors related to caring**

China has a long history of strong relationship between family members and the family is considered to be the basic social unit, and caring for a sick family member is consequently a natural part of the Chinese family's life. The way in which a person treats his or her family member is an important indication of his or her integrity. Filial piety in the Confucian tradition poses an mutual moral requirements on both children and parents. Parents are required to be kind and loving and children are required to obey their parents, protect them and bear their burdens (Hsiao et al., 2005; Wong & Pang, 2000).

The function of the family is now in a process of change due to the one-child-policy. Changes can be seen more rapidly in urban areas and more slowly in small cities and rural areas. However, families still play an important role for the average Chinese person. The family has several important political, social and economical roles. The Chinese concept of family is from a Western point of view an extended family which also involves relatives and cousins. For decades it has been the Chinese custom for extended families to live together, but this is now rapidly changing. This change will bring a new era to health care, since the younger generation today does not have the same possibility as before to take care of their parents.

The history and tradition of caring in China is closely linked to women's tradition and history. Chinese families were in the past patriarchal oriented in their approach to women's domestic and public spheres and such patriarchal dominance continues to influence women's position in rural China today (Pearson & Leung, 1995; Wong & Pang, 2000). A woman looking after a stranger in ancient China was an alien concept. The woman's place was in the home and a good woman was required to live according to the mandate of three obediences and four virtues ("San Cong Si De"). "San Cong" means that a woman should obey her father before she got married, her husband when married and her son when widowed. Si De means "De Rong, Yan and Gong" where "De" means good moral character, "Rong" proper appearance, "Yan" using proper language to communicate with people and "Gong" proper management of a family (e.g. helping husband, guiding and loving children, respecting the elderly) (He, personal communication 01.09.07; Hsiao, 2005; Pimentel, 2000; Zhang, 1987; Wong & Pang, 2000).

The traditional term "care provider" refers to family members and not to professional nurses (Hsiao et al., 2005; Wong & Pang, 2000). According to Zhan (2005) it is commonly the daughter or daughter in law of the family who cares for the elderly parents or sick family members. If there are several siblings in a family the sons may pay the sister to care for the parents, and this is in many cases the woman's income.

A woman was expected to care for her husband or for her younger brother and a man and a woman who had no familial relation was required to keep a distance from each other. It was also acceptable to hire a male servant to take care of a sick male patient and this servant's job was to do the most unpleasant and dirty work. The Chinese usually paid great attention to sexual morality and female healers were accordingly called to treat female patients. This made it unacceptable for a woman to take care of a male stranger. These traditional women healers assisted in delivering babies, prescribing and dispensing remedies and introducing sexual knowledge to women. The female healers were given little credit for their work by society (Pang, Arthur & Wong, 2000; Kao et al., 2006; Wong & Pang, 2000).

Old traditions are still present in the PRC, and it is considered important to follow the older generation's traditions. Family life and marriage in ancient China followed the husband's line. The man was more important than the woman and the married woman became a part of her husband's family. One of the key policy goals of the Communist Government has, since 1949, been

to shift the control of marital decisions over from the extended family to the individual (Pimentel, 2000). One example of an old tradition seen today in Fujian province is the tradition that a mother who had just delivered her baby must stay inside for 30 days without showering or bathing. This is called “doing her month” (“Zuo Yue Zi” in Chinese) and it is described by Holroyd and Fung (1997) Jacobsson (2001) and in personal communication with He (01.09.07). “Doing the month”- practices can be traced back to ancient China where it was a sign of how well families could support their members. However, today the tradition is followed simply because it is a tradition (Holroyd & Fung, 1997).

China’s traditions are strong and the Chinese people have a strong cultural identity, which influences social structure. The strength of the cultural influence on daily life is seen in the Chinese daily proverbs and in the common rituals, where the ritual itself is more important than the content of the ritual (Jakobsson, 2001). Many families still live in extended families and it is common that young families live together with older family members. The older generation then helps the younger generation, to raise the children and help with the household and shares life with them (Zang, 1993).

### **Economic factors affecting the health care system**

The health care system in the PRC can generally be understood as consisting of two major phases: the early phase of universal access and the current phase of unequal access. In the first phase until 1980 Chinese communist ideology supported and implemented a policy for universal access to health care. State-owned enterprises (SOE) and collectively owned enterprises where the main employers of the Chinese workers. In the SOEs the workers enjoyed stable and relatively high salaries and a highly developed welfare system. In the collectively owned enterprises the salary was lower and all welfare issues were dependent on the well-being of the enterprise itself. In the 1980s, health care reforms largely shifted from the central-planning system under communism to a free-market system of health care financing, pricing and delivery. This gave local governments more power to control their own budget. The rise of health care costs was partially related to the new incentives for medical practitioners to make profits by raising costs of treatment and medicine. Over prescription of medications and medicines and other unnecessary medical expenditures increased (Zhan, 2005).

The insurance system and the social welfare system in the PRC are not well developed. Most people who work for governmental institutions and those who

work for some companies may have some medical insurance to cover parts of their hospitalization expenses. Military employees get free medical treatment (Wang, 2005). However the unemployed, migrant workers, urban residents with a low income, and most rural residents are not covered by any medical insurance. They have to pay for all costs themselves in every hospital. The costs might be high and the patient might have to borrow money from the extended family to get the treatment paid, or even more fatally not look for help at all because of lack of financial resources. (Hassan, Shen, Y. H., Zhao & Shen, H., 2007). According to Zhan (2005) it is the son of a family who is expected to be the ultimate financial provider since a daughter usually moves to live with her husband's family.

Zhan (2005) and Hassan et al., (2007) report findings where people with low income are described as being a vulnerable situation concerning health and welfare. According to Liu and Wang (2007), patients who pay their medical expenses fully or partially themselves have a lower level of satisfaction with nursing care than patients whose expenses were paid partially to totally by an employer or by an insurance company.

An accident with a suicide bomber in Fuzhou, who in desperation of not being able to finance his medical treatment killed himself and injured 30 people, brought up the discussion about overcharge of poor people, the helplessness they feel when not getting the care needed (Hu & Dapeng 2005). People employed by the government, such as military employees, receive free treatment but according to Jing (2005), the unemployed, migrant workers, urban residents on a low income, and most rural residents are not covered by any medical insurance. Currently in China more than half of the population has no medical insurance (Liu & Wang, 2007). This situation accentuates the existing class difference in the PRC. The upper class can pay for relatively good care while the poor are referred to self-care or no care.

At a press release in 2005 Gao Qian, the Minister of Health in the PCR reported that a new health care system needs to be launched since today's Chinese health care system allows hospitals to overcharge patients for profit. He also emphasized how greedy hospitals are setting up obstacles which prevent the public from accessing and affording medical treatment. The hospitals are charging patients high fees to cover medicine costs, wages and subsidies for medical personnel, doctors and nurses, as well as new medical equipment and hospital facilities. Doctors also prescribe expensive medicine because they get profit from the medication they sell. Doctors may also prescribe unnecessary health check-ups and operations just to earn more money (Hassan et al., 2007; Wang, 2005).

## **Cultural factors regarding nursing education**

Traditionally the Chinese value education very highly (Chen, 2001) and in the PRC two major directions in nursing education can be seen. Firstly, the more Western influenced education which is documented since the beginning of nursing education in China. The first nursing school in China was established by missionaries in 1844 and was situated in Fuzhou where Hwa Nan women's college is situated today. All nursing schools were closed during the Cultural Revolution, but after 1977 formal nursing education was resumed throughout the country. From 1980 a 3 – 4 year junior college nursing education program leading to an Associate degree in nursing was set up, and later in 1983 a 5 year college nursing education program leading to a Bachelor's degree was resumed. From 1992 a graduate programme in nursing leading to a Master's degree was established. A big problem in China is the lack of nurse educators who have a higher educational background. Today several educators hold a Bachelor's degree, which gives the educations a lower standard than the Western countries. Nurses in China could only get their Doctoral degree in the field of medicine before 2003, such as Psychology and Physiology but since 2004 there is a Doctoral Programme in nursing at Chinese Peking Union Medical College. Doctoral education in Nursing will provide a good opportunity for nurse educators to develop their knowledge and the skills needed for good teaching and scholarly research (Yang Xiao Ying Director of Nursing Department at Fujian Medical University, personal communication 1999; He, 2005).

The history of nursing education at Traditional Chinese Medicine universities is similar to the above mentioned, but the history of Traditional Chinese Medicine (abbreviation TCM), which is closely linked to nursing education, is long hand embedded in Confucianism, traditions and beliefs. The classic "The Yellow Emperor's Medical Classic" was written more than 2000 years ago. Chinese nurses learn the theory and clinical practice of acupuncture as a part of their training. According to the philosophies that undergird TCM they believe that acupuncture can help restore harmony in the body and thus aid a person's curative powers. Because these traditions and beliefs are understood and generally accepted by all, Chinese patients share a common philosophy with their health care providers according to Chen (1996). Consequently, acupuncture is more successful in relieving the symptoms of stress and anxiety such as pain discomfort and nausea. Traditional Chinese medicine emphasizes prevention and holism, and guided by TCM Chinese Nursing is a subject combining specialized theory and technique with traditional features.

TCM hospitals were established in the 1950s, and research in the field of nurs-

ing also started at that time. In the 1950's they also started combining Western Medicine with Traditional Chinese Medicine. Traditional Chinese Nursing developed rapidly in the 1980's and became a new subject of interest. Guided by the basic TCM theory, Chinese Nursing became an area with its own theory, technique and special features. In the PRC there are 2297 TCM hospitals and 7 TCM Nursing Schools. 29 Universities in China offer education in Traditional Chinese Medicine (Tian Yun Li Director of Nursing Department University of Traditional Chinese Medicine, personal communication 1999).

There is a clear distinction made between family carers and professional carers. In a study conducted by Pang, Wong, Wang, Zhang, Chan, H., Lam and Chan, K. (2003, 79) nursing in China is defined as following:

*Nursing means to understand the dynamic health status of a person, to dialectically verify health concerns, and to devise interventions with the goal of assisting the person to master the appropriate health knowledge and skills for the attainment of optimal well-being.*

The language used in the definition such as “dynamic health status” and “dialectally verify” is rooted in the theory of Traditional Chinese Medicine (Pang et al., 2003). The authors continue by explaining that nursing focuses on the dynamic, relational and contingent character of human processes and their interdependent relationship. Negative statements about both profession and workplace were also seen in the study mentioned above, for example, the informants complained about being seen as the doctor's assistant which left little scope to develop nursing.

Kao et al., (2006) present a holistic view of a Chinese nursing metaparadigm, constructed from reflections of Chinese philosophies and Rodgers' nursing theory of unitary human being. Harmony is an important value embedded in Chinese philosophies and this is seen as an important concept in the model. Kao et al emphasize the importance of the nurses' own harmony in order to be able to change the harmony status of the patient. Harmony or equilibrium is seen as health, and disequilibrium or disharmony is seen as illness. Nursing is characterized by recovering harmony or compensating disharmony. During periods of harmony, nursing intentionally promotes harmony, and during times of disharmony the nurse's task is to transform the disharmony into harmony. The model uses concepts and ideas both from traditional Chinese philosophical values and Western ideas of nursing.

Today the PRC is opening up to student and teacher exchange with the Western

world and this is changing nursing education. Nursing research is expanding and a huge development can be seen in articles about nursing written by Chinese researchers. For example He (2006) has in her research focused on non-pharmacological methods in children's postoperative pain relief in China. One of her findings concerning nursing education is that there is a need to provide the nurses with more education in pain management for nurses.



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## METHOD

### 6. Interpretative ethnography as an overall methodology for the study

Research methodology can be broadly categorized into either qualitative or quantitative, depending on approach and perspective. The qualitative research-approach, as well as methods deriving from philosophies such as phenomenology and hermeneutics, has become more frequent in nursing research during the past decades. This study takes a qualitative research approach<sup>38</sup> and the overall method is interpretative ethnography inspired by Geertz (2000a). Interpretative ethnography leans on a hermeneutical approach and strives to discover and interpret the meanings of observed social interactions (Geertz, 2000a, 2000c). The hermeneutic approach is often used in Caring Science tradition as research method (Eriksson & Lindström 2007; Eriksson et al 2007).

Geertz (2000a) in his description of inscribing meaning to actions, refers to Ricour and discusses the process of writing down events and social interactions. Events and interactions exist only in the moment, but by writing them down one brings them into an account which exists in its inscriptions and can be reconsulted. Through this the ethnographer tries to understand the context. A good interpretation of something consequently leads to the core of the interpretation. Geertz continues by describing the idea of culture as a web of significance that the human being itself has spun, and emphasizes that an analysis of culture has to start with a search for the meaning that people ascribe to their actions (who they think they are, what they think they are doing and how they are doing it) (Geertz, 2000b). In this study the hermeneutic approach is seen in all phases from the handling of the collected narrative material, which is transcribed verbatim, and in the observations which are transcribed into words aiming at reconsulting them in the analysis phase. The intention is to grasp the meaning of the events observed and investigated and through this to create a deeper understanding of the experienced events.

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<sup>38</sup> Qualitative research examines phenomena about which little is known and the researcher uses in-depth methods to describe the dimensions, variations and importance of phenomena (Polit & Hungler, 1999). Miles and Huberman (1994) define how a qualitative research is conducted through an intense contact with a field or with life situations. These situations are typically ordinary or normal life situations, which reflect the everyday life of individuals, groups, societies and organizations. The experience, expression, interpretation and understanding of suffering are not a well investigated areas transculturally. The application of a theoretical perspective developed in a Western culture on an empirical study in an Asian culture is a rare method of conducting a nursing research. The knowledge acquired is therefore not broad, and a qualitative approach is necessary.

According to Geertz (2002a), to discover people's self-conception and their perceptions of their own actions, one must gain a working familiarity with the frames of meaning within which they enact their lives. To discover people's self-conception and perception of their own actions neither involves feeling anyone else's feelings, nor thinking anyone else's thoughts, nor does it involve becoming native. It involves learning how, as a foreigner with a world of one's own, to live with them. This can be seen as adapting a naturalistic approach and in this study it is seen in the procedure for collecting data material.

A naturalistic approach to ethnographical studies is rooted in anthropology (Hammersley & Atkinson, 1995). The authors describe how naturalism posits that the social and cultural world is distinct from the physical world and should be studied in its natural state in order to remain as true as possible. Human actions are influenced by socio-cultural meaning such as beliefs, values or rules that are dependent on context or situation. According to Denzin and Lincoln (1994) naturalism is linked to the constructivist view which posits that multiple realities of phenomena are constructed from the everyday world of experience.

To understand constructed reality, one must interpret it within the context in which it arose. According to Geertz (2000a), there is a need to stay grounded when constructing cultural theories; the tension between the theoretical part and the empirical part gets stronger when one gains access to the world of informants, and the gained information consequently can be interpreted more thoroughly. The essential task is not to codify abstract regularities or to be able to predict them, but to make "thick descriptions" possible. Thus one should not generalize across cases but within them. Culture and the analysis of it are not part of experimental science in search of law, but instead part of interpretative science in search of meaning.

A central idea, as mentioned earlier, in interpretative ethnography is the construction of "thick descriptions". The thick description of a situation does not only describe the context of the action, but is based on the intentions or meanings that structured the action and its development. The presentation of the action eventually forms a text which can be interpreted. In order to grasp the meaning of a situation, one must put together the compared and contrasted "pieces" of what is seen, and finally construct a meaning of the event - a thick description<sup>39</sup>. In order to understand a culture, one must interpret it; the mean-

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<sup>39</sup> Geertz (2000a, 6-7) describes how three boys' rapid contraction of eyelids can be understood differently. To only describe the contraction is a thin description but to be able to describe whether the contraction of the eyelids is done deliberately, to someone in particular, to impart a message, to do it according to a social established code or without cognizance (parodist, winker, twicher...) is a thick description. It then forms a stratified hierarchy of meaningful structures in terms of which twiches, winks, fake-winks, parodies and rehearsals of parodies are produced, perceived and interpreted.

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ing must elucidate the process of constructed meaning and clarify what and how meanings are embodied in the actions of informants.

To prepare an interpretation is to construct a reading of these meanings; it is to offer the researcher's construction of the constructions of the informants<sup>40</sup>. The task of ethnography is not only observation and description but the inscription or "thick description" of these meanings ascribed to human actions (Geertz, 2000a; Schwandt, 1997).

The validity or authority of a given observation is determined by the nature of the critical understandings that it produces. These understandings are based on glimpses and fragments of the culture in action. Any given practice that is studied is significant, because it is an instance of a cultural practice that has happened in a particular time and place. This practice cannot be generalized to apply to other practices, its importance lies in the fact that it instantiates a cultural practice, a cultural performance (storytelling) and a set of shifting conflicting cultural meanings. An ethnographic description is interpretative, and it interprets the flow of social discourse (Denzin, 1997). You either grasp an interpretation or you do not, see the point of it or do not, accept it or do not (Geertz, 2000a, 24).

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<sup>40</sup> What the researcher calls "data" can be defined as "the researcher's own construction of people's constructions of what they and their compatriots do". This can be obscured, since most phenomena that we need to comprehend (e.g. an event, ritual, custom or idea) are indirectly given as background information before the phenomena in question is directly examined Geertz (2000a, 9).

## **7. Ethical considerations regarding the empirical part of the study**

The International Centre for Nursing Ethics (ICNE) suggests five broad principles for developing international guidelines in research. The five principles are: respect for people, beneficence, justice, respect for community and contextual caring. They fall into traditional ethical guidelines based on beneficence, respect for human dignity and justice.

The first principle of respect for human dignity can be described with the participants' right to self-determination and full disclosure. The second principle of beneficence can be described as being free from harm and exploitation, as well as society's right to benefit from research results. The third principle of justice can be described as the right to fair treatment and privacy. Olsen (2003) discusses cultural differences in international nursing research and finds that some types of research, which cross national boundaries, have a higher potential for ethical difficulties than other. One of the risks is that the country or culture where the investigation takes place is not used to nursing research, and therefore has no tradition of protecting vulnerable groups in research.

The fourth principle, suggested by ICNE, is respect for community, and this principle goes beyond the standard application of ethical principles in nursing research. This principle recognizes that individualism can often be inappropriate in cultures where the team, family, or group is valued very highly and the individual's rights are not equally important. In this research both patients and their families were involved. The principle also awakens the discussion of reporting results from research in a culture which is not well known to the researcher. Is it possible to protect the community from the harm that a misunderstood result could cause? This ethical question lies in the interpretation of results were the researcher may see the culture in question through a foreigner's eyes, and evaluate the findings based on another cultural understanding, which is the fifth principle described.

The last principle concerns contextual caring, and within this principle ethnocentrism has to be discussed. Contextual caring has to be interpreted and understood and not evaluated based on other cultural values. To avoid harming a community and its contextual caring by misinterpretations and misunderstandings (cf. Freeman, 2000) this research was read prior to publishing by two independent people who are native Chinese. Their comments were taken in consideration.

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There are three initial conditions according to Olsen (2003) for conducting international research:

1. The local community is offered an early opportunity and an ongoing system to provide input into the purposes, goals and methods of the research.
2. The research design generates knowledge that has the potential to benefit the community or population providing the participants.
3. There is an ethically justifiable reason to target the population from which participants will be recruited.

In this study the three conditions were taken into consideration as following: the local community, the hospitals and universities involved, was given opportunity to read the proposal for the study and to get familiar with the research questions and research methods before approving the research application. Since nursing research is not common at the involved hospitals, there was no readymade structure for handling these matters and the aim of the study and the procedures for conducting the study was discussed with both the Presidents as well as with the Heads of the Nursing Department of the hospitals involved, previous to the conduction of the study. A mutual agreement of how the study should be conducted was reached. The study was approved by the Head of the Nursing Departments at the hospitals which were involved in the study. The documents regarding the approval of conducting the study and informed consent are filed at Åbo Akademi University, Institution of Caring Science<sup>41</sup>.

The second condition concerns the benefit of the research. The study has to benefit a community or population which provide informants. To facilitate the benefit of the study, it was written in English. The study highlighted the culture care procedures and structured them into interpretative patterns and compared them to theories and previous research in the same area. This can initiate a development of caring practices which can influence the population from where the participants are recruited. The study also benefits the development of Caring science and can inspire nurses to continue with development of cultural competence in caring.

The third condition concerns the choice of informants. There is a need to jus-

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<sup>41</sup> The filed documents are the application for permission to conduct the study at three hospitals in Fujian province and the permission for conducting the study at the same three hospitals. Documents regarding verbal informed consent are also filed.

tify the reason for choosing a specific target group. In this study the target group consisted of nurses, patients, relatives and Hu Gongs. The above mentioned groups of participants have an insider's view of suffering and caring in a Chinese setting and they were therefore chosen as informants. The participation was voluntary and the participants could withdraw whenever they wanted during the process of collecting data. The participants are only known to the author, the co-researcher and the Head Nurse who chose the participants.

### ***Cultural imposition and blindness***

Cultural imposition is a concept used among authors in the field of transcultural nursing<sup>42</sup>. The concept was coined by Leininger in the mid 1950's and defined as "the tendency of an individual or group to impose their beliefs, values and patterns of behaviour on another culture for various reasons (Leininger, 2002a, 51). Cultural imposition is a serious and largely unrecognized problem in nursing which emerges from cultural ignorance, blindness, ethnocentric tendencies, biases, racism and other factors according to Leininger (2002a). Leininger continues with describing that cultural imposition can occur between nurses and patients in situations where the nurse and the patient not have an equal position, and the nurse shows power, influence and authority. Vulnerable patients are more exposed to cultural imposition. Cultural imposition is closely linked to nursing ethics and dignity in nursing care since it is a description of how professionals abuse the confidence they are given as nurses.

"Cultural imposition" is mainly used in literature when discussing nursing care, but it is equally important when conducting research. It can be linked to the five principles for developing international guidelines in research described above. To avoid cultural imposition in a research process, one should be humble, open-minded, and be guided by the participants. An understanding of cultural values, norms and beliefs prevents cultural imposition. When conducting a study in a foreign culture, it can be a sign of cultural imposition to compare the health care organisations, the conduction of care and nursing care in the culture investigated with other systems in other countries. This is particularly risky when using a theoretical perspective and basing theoretical knowledge on developments in caring science in Western cultures, since the empirical study is conducted in an Asian culture.

Ethnocentrism is one way of showing cultural imposition. All cultures are different and all cultures have their own values, which are not completely under-

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<sup>42</sup> The concept cultural imposition is used by Andrews (1999), Kleinman, Eisenberg and Good (1978), Lea (1994) and Leininger (1978, 1984, 1985, 1991).

stood by a foreigner. Geertz (2000a) claims that the besetting sin of interpretive approaches to anything is that they tend to resist. This is shown in research where an ethnocentric view is predominant<sup>43</sup>. The researcher's cultural blindness might lead to incorrect interpretation and understanding of the patients', relatives' and nurses' expression of, in this case, care, caring and suffering. Cultural blindness can be seen in the erroneous reporting of the findings from a study, where the descriptions are tainted by the researcher's own expectations. Cultural blindness refers to the inability to know another culture because of misunderstandings. Prejudice can be made evident through cultural blindness.

Communication requires cultural competence, since the interaction crosses different cultural borders. Cultural competence involves intercultural communication, and the key is not only to learn the language but to understand the norms and rules of the culture. Anxiety, ethnocentrism and the assumption of similarity instead of difference are barriers to intercultural communication (Alexis & Chambers, 2003; Howard, Andrade & Byrd, 2001; Roux, 2002). Ethical dilemmas occur when health care providers lack awareness of the value systems of patients that differ from their own (Donnelly, 2000; Searight & Gafford, 2005), a fact that can also be applied to nursing research.

### *Violation of dignity*

Human dignity is a basic concept in caring science (Edlund, 2002) and one of the fundamental ethical considerations concerning nursing research. The ontological assumptions, which constitute caring science, include human dignity. Dignity is contextually closely linked to health and suffering (Edlund, 2002; Eriksson, 1993, 1994, 1995,) and it lies in the professional nurse's ethical code not to violate the participant's dignity (Burns & Grove, 1997; Hanssen, 2002; Polit & Hungler, 1999) which is also an important ethical code in nursing research.

The carer has the intention to respect the patient (Hansson, 2002) and the care can be both planned and delivered in such a way that the patient's dignity is violated due to "cultural blindness" (cf. Fadiman, 1997). This can be applied to an ethnographic study regarding data collection, research questions and interpretations of situations. Edlund (2002) in her study defines how dignity can be understood and states that one can reach understanding through recognizing

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<sup>43</sup> Bodley (1994, 110 – 12) describes Hippler's work among Australian aborigines in 1978 as typical research where earlier interpretations of the culture, which fall into the category of ethnocentrism, taint a new research and violate the culture of a population. Hippler describes the Australian aborigines as infantile and superstitious with difficulties to separate dream from reality. He builds his research on Wake's research from 1872, where the above mentioned characteristics of Australian aborigines were presented.

how the word dignity is used in a language. The understanding of dignity is different in different cultures since it is not used in an exactly similar way in all languages, due to the languages' dependence on the human beings experience of her reality. Hanssen (2002) discusses how this violation of dignity occurs unintentionally due to lack of knowledge, and how the nurse has a desire to do what is morally and ethically right in caring situations.



## 8. Procedures of the empirical part of the study

In the following chapter the data collection and data analysis methods used will be discussed in relation to ethical and validation issues. The hospitals participating in the study are not for example accustomed to being involved in nursing research or to international researchers. The leaders of the hospital approved the study, chose the nurses who guided and assisted with choosing informants as well as with following the data collection. Below in figure 2 the conduction of the empirical study is visually presented with the different stages in data collection and analysis shown according to a time line.

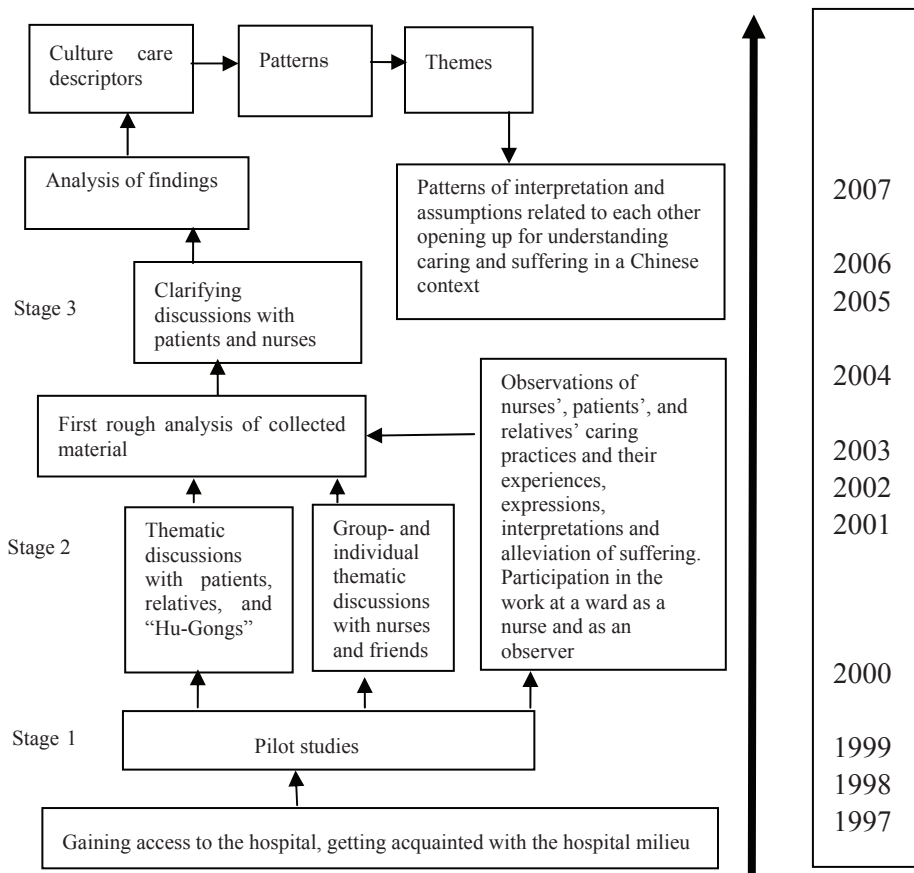


Figure 3. Conduction of the empirical part of the study.

The figure should be read from the bottom to the top. On the right side of the figure is a timetable which shows how the research has progressed. However, writing field-notes are a re-occurring feature in all the phases of data collec-

tion, and it reflects the experiences, observations and reflections during data collection and analysis although not mentioned especially in the figure. Figure 3 describes the different stages in data collection as well as in analysing the data.

Roper and Shapira (2000) mention dimensions the researcher must explore to achieve subjective adequacy within ethnographic observation. The first dimension mentioned is time the researcher has to spend enough time in the setting to learn about people, behaviours, and events and to be accepted as a member of the group. From 1997 – 2000 the author visited Fujian province 4 times and stayed 2 – 3 weeks each time. During this time a network of friends was built, which helped in gaining access to the hospital milieu in Fujian province. In 1999 the research proposal was presented at a nursing conference in Beijing<sup>44</sup> and the pilot studies were conducted the same year. The cultural keys were simply learned by lecturing as well as working and discussing with people there. However, time spent in the culture was limited. A two to three weeks' stay in a foreign culture is a short time for learning to grasp the daily life. Possibilities to stay in touch with friends in China by mail have consequently been of great importance. In 2002 the author visited Fujian province for 3 weeks and the first data collection with patients, relatives, Hu Gongs and nurses was conducted. "Hu Gong" is translated to English "caring worker". They are hired by patients or relatives to take care of the patient if the relatives cannot stay with the patient. A Hu Gong has no formal medical or nursing education and they are strangers to the patient. They are not employed by the hospital and the hospital carries no responsibility for the care they give. During the period 2003-2004 the author visited Fujian province twice and stayed for 2 weeks each time. In 2005 clarifying discussions with patients, relatives, Hu Gongs and nurses were held during a 2 week long stay.

The place where the data collection is done must according to Roper and Shapira (2000), be selected based on both the research question and on the possibilities to take part in the informants' social life. The researcher needs to create situations that help the informants to trust the researcher. In this study the empirical part was conducted at three hospitals in Fujian province. One of the hospitals is linked to the University of Traditional Chinese Medicine (TCM) and the two others are linked to Fujian Medical University, which has a Western orientation in medical and nursing care. TCM is nevertheless a natural part of the Western-oriented hospital as well, and the idea is neither to compare two

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<sup>44</sup>"The Nurse as A Caring Scholar: The New Wave" arranged by Department of Nursing and Health Sciences, The Hong Kong Polytechnic University, School of Nursing, College of Medicine, National Taiwan University and Chinese Nursing Association.

different treatment philosophies nor to compare different cultures at different wards in this study. The different philosophies that undergird the two hospitals will not be discussed further in this study unless there are obvious differences and there is therefore a need for clarification. The both above mentioned universities have several hospitals linked to the universities.

The place is of importance when conducting an ethnographic study and Roper and Shapira (2000) discuss the importance in choosing the correct environment for data collection. A hospital might not be the best place to build trusting relationships, but in this research this was the only option. The place for observation and conversation is selected by the hospital, and that gives a specific framework to the study. The observations cannot be validated, which according to Roper and Shapira (2000) is one of the important dimensions in ethnographic study. The interpreted meanings of the observations can however be discussed with the informants and through this procedure some validation can be done. This validation is done through clarifying questions and discussions with informants, in order to avoid bias, which is also an important dimension to consider in an ethnographic study.

Language is also an important dimension in an ethnographic study (Roper & Shapira, 2000). If the study is done in a language which is foreign or not very well known to the researcher, the help of a translator is needed. Unfortunately, little is written about the interpreter's or translator's role in conversations and even less is written on language difference within a group of people who do not speak the same language as the researcher. Consequently the researcher is given minimal guidance for conduction of a research when the language not is shared with the informants. The information given by the translator is translated and understood, based on the translator's worldview. The languages might not be interchangeable and it is then impossible to give a word-for-word-translation, since the content would lose meaning. Temple and Edwards (2002) suggest a model where translators/interpreters are seen as key informants and the process of data collection is not done through the translators but with the translator. The interpreter/translator should be seen as an informant, and be used as someone who works across boundaries. The solution used in this study was to work with the translators and collect the data with them. This procedure transforms the translators into co-researchers. This was possible in this study, since the translators are familiar with the Finnish and the Chinese culture as well as the theoretical perspective of the present study.

## Data collection methods

The data collection has been in process for many years and several data collection strategies within ethnographical research have been used. Both unstructured and participative observations were used. Discussions, both formal and informal were also used. The formal discussions have a theme and the informal discussions' topics are broad and the focus is on the informants own story telling and life experience. Field notes written during the study are analyzed and used as data material throughout the research. In the beginning of the fieldwork, the researcher was a stranger to the people participating in the study. It takes time to learn to know each other.

Three stages in the data collection can be observed. The first stage is characterized by getting to know people, gaining access to the hospital milieu. A study<sup>45</sup>, concerning nurses understanding and experience of suffering among patients was done by students at Svenska Yrkeshögskolan, University of Applied Science (2001). The study was carried out during 2 of the students' practice at one of the hospitals in Fuzhou, involved in the present study. This study is a Bachelor's thesis, and is a part of the authors pre-understanding gained for this study. Methods planned for data collection were tested and two pilot studies were conducted in 1999. The first pilot study concerned observation of patients and nurses at a ward. The aim of the pilot study was to find out if it was possible to gain knowledge at a hospital where the language was not shared by the informants, when using observation as data-collection method. The aim of the second pilot study was to find out if the study would gain from using group discussions as data-collection method. The pilot studies were evaluated and the methods were found to suit the research questions. The chosen data-collection methods could consequently be used.

Stage two in the data collection consisted of thematic discussions with individuals or in groups as well as conversations with nurses. Observation, participation and thematic discussions with patients, relatives and Hu Gongs were simultaneously done. Hu Gongs were not a target group for the study at the planning stage, but due to their importance in caring for patients in a Chinese context, two Hu Gongs were also included in the study.

The third stage of data collection was conducted after a first rough analysis of findings. In 2005 a clarifying data collection was conducted. The data were

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<sup>45</sup> The study was written by students Appel, Ekström, Jungell, Lemström, Mitts, Nyström, Sarin and Seiplax (2001), and is named: "Cross-cultural understanding - how nurses/student nurses interpret and alleviate suffering in six different countries". One part of the study was conducted in China.

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collected using same methods as before, observations, discussions and field notes. In the third stage nurses, patients, relatives and Hu Gongs participated.

## **Observation, participation and field notes**

Observation is a central strategy for data collection in ethnographic research. In this research the unstructured observation is predominant. Mulhall (2002) describes unstructured observation as a data collection method where the researcher wants to understand and interpret cultural behavior in a specific context.

Unstructured observation is not unsystematic or negligent. The field is entered with curiosity and with questions. The role of the researcher, as well as the questions, changes over time. Unstructured observations carry the tenets of the naturalistic paradigm and it is impossible to separate the researcher from what is being researched (Mulhall 2002). Savage (2000), as well as Mulhall (2002) and Pellatt (2003) discuss the fact that the researcher's involvement in the data collection cannot be separated from the researcher's theoretical or epistemological suppositions. In this study, the observed phenomena are filtered through what is chosen (consciously and unconsciously) as the field of observation (the theoretical perspective for the study, the pre-understanding, the competence and interest of the researcher influence what is seen and what is obscured) and how it is analysed. When collecting data through observation the researcher influences the situation and according to Pellatt (2003), there is no way of removing the observer from the research in naturalistic settings. The researcher is not able to put him/herself "in brackets" and try to be objective and therefore must be aware of the subjectivity in the data that is collected, interpreted and understood.

The benefit of observation in an ethnographic research is obvious, since the observations reflect and clarify the practices, meanings and values that people in a context give words to, in a discussion or interview. According to Hammer-slay and Atkinson (1995) and Paterson, Bottorff and Hewat (2003) observation offers a deeper understanding of the participants' explanations of what they do and why they do it. This fact is also described by Geertz (200a), who says that ethnography is like "reading a manuscript" and by writing events down the researcher gives the events a meaning.

An ethical dilemma in collecting data by observation and participative observation is that of informed consent. It is impossible to inform everybody participating in an event or at a ward about the research, which involves participants.

In this study there are participants who were not aware of being informants. The formal ethical principles were followed (informed consent given by the hospital leaders, and followed up by the nurses at the wards where the study took place), but the ethical principle of letting everybody withdraw from a study cannot be carried out. The researcher carries a serious personal responsibility for not causing harm to those voluntarily or unconsciously participating in the study as informants.

Field notes are essential in an ethnographic research, and they follow the observation and participative observation. Mulhall (2003) discusses the different ways of understanding “the field” and how the field can be viewed as a natural entity or a constructed entity. The field can be defined as a natural entity, which needs to be objectively described by the observer, or as something we construct through practical transactions, activities of data collection and through the literary activities of writing field notes and analytic memoranda. This is also discussed by Pellatt (2003), but then in terms of what the field does to the researcher and how the field changes the researcher and influences him/her emotionally. When viewing the field as something constructed which has great influence of the researcher, the researcher’s paradigm and pre-understanding will be of crucial importance to the reader when validating the written report. In this study the field notes carry elements of pre-understanding since they are already an interpretation of what is seen and perceived. This indicates that the field notes and observations actually carry elements of a constructed reality.

## **Interviews, discussions and conversations**

Interviews are commonly used in nursing research and information about various interview methods can be found in articles and books which describe interview methods. When conducting an ethnographic study the interview is carried out from a particular perspective. Interviews in ethnographic research can be focused but seldom structured. Ethnographic interviewing is aimed at discovering the general cultural knowledge of the informant or their knowledge of a specific topic (Sorrell & Redmond, 1994). The outcome of an interview is often a story. Interviews can be used to validate and clarify observations (Leuning, Small & van Dyk, 2002; Roper & Shapira, 2000), which indicates that ethnographic interviews do not follow a structured form; rather the opposite. Interviews in ethnographic research have the form of a discussion or dialogue, where the aim is to learn from the informants by asking questions regarding everyday life and specific topics. Roper and Shapira (2000) describe three forms of ethnographic interviewing; group, formal and informal interview. Sorrell and Redmond (1994) describe the ethnographic interview as a se-

ries of friendly conversations which have a clear and specific research agenda. Friendly conversation can be understood as a form of informal interview. In this study much data was collected through friendly conversations where the theme was very broad.

In the present study group discussions were conducted and they carry elements of focused group interviews, and the techniques for conducting the group discussions are borrowed from the technique of focus group interview. A focus group interview is a qualitative data collection method using discussion with a small group of people (usually 4 – 12) in a comfortable, non-threatening environment in order to obtain perceptions about a given problem, area of interest or topic of study (McDaniel & Bach, 1994). A focus group interview is a focused interview where one turns to people especially chosen for this occasion. Robinson (1999) stresses that focus group methodology is an interviewing technique, and is consequently not a discussion, problem solving session or a decision making group. However, Tillgren and Wallin (1997) use discussion instead of interview and point out that a group process gives the possibility for participants to discuss and form their opinions. There is no intention to reach consensus in a focus group. In this study the groups were not chosen by the author (they were chosen by the hospital leader, and language proficiency was a criteria considered, as well as nursing experience) and the occasions have the form of a discussion. In this study the denomination “group discussion” is used instead of “focus group interview”.

The technique for a focus group interview has mainly been used to gain information from the members of the group and the group interaction has seldom been analyzed. Marttila and Stjerna (1997) discuss the use of focus group interview as a data collection method and the analysis of the collected data could be done in several ways: 1) focusing on the content of the interview 2) focusing on the dynamics between the group members 3) focusing on both content and group dynamics. According to Robinson (1999), the combination of members in a focus group may lead to polarization. Conflicts may then arise and only little information can be gained. The ethical dilemma in a focus group interview is confidentiality, which could be a problem between participants when interacting in a group situation. The moderator is the person who should help people to express their knowledge, but still not let anybody in the group session misuse the gained information. In this study the main data collected was focused on the content, but to avoid bias, depending on the composition of the group, emphasis was also put on the dynamics between group members. The moderator plays a key role in the conduct of the focus group and one of the

most important issues in the criticism of this interview technique is the role of the moderator (Twinn, 1998). When the group discussions in this study were conducted, the author acted as a moderator twice and as an observer once. One co-researcher acted as moderator once. A co-researcher was present at every discussion.

## **Informants participating in the study**

Patients, relatives, Hu Gongs, nurses and other people, who have knowledge about this area, are informants in this study. The group “other people” consists of friends of the author and people outside the hospital, who have previously been relatives to a patient and have emic knowledge of the situation. Nurses, patients, relatives and Hu Gongs are key informants.

Key informants are people who have been selected because they are most knowledgeable about the domain of inquiry. They are believed to reflect the norms, values, beliefs and general way of life within the culture, and are interested in and willing to participate in the study. General informants are usually not as familiar with the culture or phenomena as the key informants, they do, however, have general ideas about the domain of inquiry and are willing to share their knowledge (Leininger, 1991; 2002b, 2005b; Roper & Shapira, 2000).

When conducting an ethnographic study the researcher needs to get immersed in the culture and this provision is difficult to achieve as a foreigner. Guidance and translators are needed. In this study, four nurses have acted as co-researchers. The co-researchers have insight into both the Finnish culture and the Chinese culture, and speak a common language with the author as well as fluent mandarin and the local dialect used in Fujian province.

### ***Nurses and Hu Gongs as informants***

The author has learned from the informants through conversations, observations (both participative and plain observations) and group discussions. Thematic group discussions which were planned beforehand are held with nurses. The members of the groups were elected by the leaders of the hospitals and the groups consisted of nurses who understood and spoke English. The groups consisted of 7–9 participants/group and besides the author a translator/co-researcher was present at every meeting. A majority of the participants had an education on Bachelor’s level and three of the participants have an education at Master level, and their age ranged from 25 – 40, and several were young.



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Four of the participants had worked outside the PRC, in Japan, South Africa or England within the last five years.

Three different groups of nurses from three different hospitals were gathered and the meetings lasted for 1½ - 2½ hours. The meetings were held in the hospital's meeting room during work time. The head of the nursing department was present at the first session and acted as a translator if needed. The discussions were taped at all three sessions and transcribed verbatim by the researcher.

During session one and two the researcher acted as moderator and the co-researcher took notes during the second session. During session three the co-researcher acted as moderator and the researcher took notes. The settings were well suited for focus group discussions, every occasion was organized around a table in such a formation that participants could see each other, and the moderator and co-researcher could see everybody. The sessions were held in a friendly and open atmosphere and the nurses were willing to share their knowledge. Although the head nurse was present at one session, the nurses never seemed to be afraid to speak out. Since the group discussion was held in a culture which was foreign to the researcher the interpretation of the situation might be wrong, however nothing indicated that it was negative to have the nurse leader as a participant in the group. Tea and fresh fruit were served in every meeting, an arrangement that was made by the hospital. The participants were given a small gift by the researcher after participating in the discussion.

The data collection with nurses was followed up 3 years later. In 2005 a group discussion in one of the original groups was held and beside the group discussion individual discussions with nurses who had participated in the first stage of data collection were conducted. The second data collection, named as stage 3, was a clarifying discussion through which the author could validate findings from a first rough analysis of data. Altogether 26 nurses participated in the focus group discussions and 13 nurses participated in the follow up- discussions.

To invite Hu Gongs as informants was not a planned strategy, but during the observations at the hospitals this group turned out to be very important in the care for patients. Two Hu Gongs participated in discussions, one female and one male. They had worked for a long time as Hu Gongs and had various experience of the job. The female Hu Gong had worked for the same patient for more than one year and the male Hu Gong had shifted patient several times the last year. The discussions were held at the hospital in a meeting room in a friendly atmo-

sphere. One co-researcher was present. The Hu Gong and the co-researcher did not know each other. The discussions lasted for about 45 minutes each.

### ***Patients and relatives as informants***

The patients and relatives acted as informants in observations and conversations. The author, the co-researchers and the nursing leaders selected the patients who were invited to be informants in conversations. The selection follows the criteria set by the author. The including criteria were that the patient had been hospitalized for at least one week, that he or she was willing to participate and that the patient not be seen as too vulnerable. The relatives were not selected separately. The patients were all on medical, surgical and rehabilitation wards. Some of the wards were medical and surgical intensive care units. The patients varied in age, reason for admission and language skills. The discussions with patients were done together with a co-researcher. The discussions were held during two weeks in year 2002 and one week in 2005. All together 15 patients and their relatives were involved in discussions and conversations at the hospitals. Six of the patients were seen several times during the researcher's stay at the ward.

Before discussing with the patient ethical issues were discussed with the co-researcher and the importance of not letting the patient be harmed was pointed out. The author was introduced to the patient, and the aim of the study was presented to the participant. Informed consent (verbal) was gained (the co-researcher translated the form and asked the participant of informed consent). The use of tape-recorder was also discussed and used when accepted. No informant refused the use of tape recorder. The participants participated voluntarily, and they could withdraw at any point. The interviews were done with the intention not to cause harm to the informant.

The informants were at tumor, medical and rehabilitation wards and at Intensive Care Units. The patients are presented below and given fictive Chinese names in this study, and the names have no connection to the real person. The strategy, to present the patients and relatives participating in the study was adopted with the aim of giving a face to the voices.

Patients at the Western medicine oriented hospital:

Patient 1, Mr Wu Ang-Nai, is about 65 years old and his wife is the same age. They are both architects. Both participate as informants. Mr Wu Ang-Nai has been in the hospital for 3 months in total, but has occasionally been at home.

He has series of 5 days including 6 treatments with chemotherapy. He has known about the disease (cancer) since May 2003. Both wife and husband are retired and only work part-time.

Patient 2, Mr Liang Bi-Rong is about 55 years old and his wife is around the same age. Both are well educated and belong to the small Christian society in the province. The man has known about his disease (cancer) for 6 months and he is in hospital while he gets chemotherapy. Both men and their wives participate as informants.

Patient 3, Mr Xin Fan-Ju is a farmer and in good condition. He has a tumour in his stomach and has undergone surgery. He has now had his first chemotherapy after the surgery one year ago.

Patient 4, Mr. Wang Kai-Hao is a young boy (about 11 years old) suffering from cancer, which has spread to the lung. The prognosis is not good. He has supportive IV infusion. His appetite has decreased during the last months and he does not want to eat anything. He has metastasis in the bones and in the lung. He is given a lot of infusion before and after chemotherapy to prevent his kidneys from getting damaged, and in case of unexpected side effects of the medication. The father and mother are with him at the hospital. The boy is just lying in bed he does not want to play anymore, just watches TV. The boy has a pain in his back and does not want to move. His mother helps him with everything. Both father and mother act as informants.

Patient 5, Mr. Yu Tiao-Kai is 82 years old and has a heart problem. He is a patient at the ICU, and his wife spends all the time that she is allowed at the ward with him.

Patient 6, Mr. Tong An-Rui is a man at the age of 66. He is suffering from hepatitis and he has been in the ward for four weeks. He has a room of his own at the hospital. His wife is a doctor at the hospital and I can see from the conditions in the room that it costs more than ordinary rooms. The man is dressed in his own clothes and currently seems to be in good condition.

Patients at the hospital linked to Traditional Chinese Medicine:

Patient 7, Mrs. Bei Su-Rou is a female patient who has been healthy for most of her life she is 82 years old but looks younger. She is now getting treatment for her dizziness.

Patient 8, Mrs Hong Dan-Kun is also a female patient. She is a 65-year-old teacher who has problems with high blood pressure and pain in her shoulders.

Patient 9, Mrs Jia Em-Ei is 70 years old and is at rehabilitation due to stroke. She was firstly hospitalized one year ago and is now partly recovered. She still needs treatment for her paralyzed hand.

Patient 10, Mrs. Ou AINU-An is an old lady suffering from herpes zoster which is causing her much physical pain. Her daughter is often together with her in the room and she also acts as informant.

Patient 11, Mr. Tang En-Rong is now 60 years old, but seems much younger. He is getting treatment for weakness and dizziness (and as I can understand he is recovering from stroke, and still has problems with detailed co-ordination in his right hand).

Patient 12, Mr. Ran Kai-Nui is soon 80 years old and suffers from pain in his muscles.

Patient 13, Mr. Wu Hong-Li is a 40 year old man suffering from pain in his neck and back after an accident.

Patient 14, Mr. Hu Jian-Heng is a 51 year old man suffering from pain in neck and back due to long office work. His pain is chronic and he is in the hospital for pain relief.

Patient 15, Mr. Wu Kai-Zhen is a 26 year old man who suffers from pain in his back and is undergoing treatment.

The patient's relatives who acted as informants are presented above. Further other relatives are also participating as informants. The other relatives and informants (7) are persons who are known to the author and who have been relatives at hospital, caring for a sick family member. The other relatives acting as informants have participated in informal discussions about generic care practices aiming at alleviating suffering. The data collection with the other relatives have been ongoing during the whole period of research.

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## 9. Analysis and interpretation of the findings

The purpose of ethnographic analysis is to organize the data and then make sense of what is learned. According to Bodley (1994), it is impossible to know any culture except from the inside, as a native member - the emic view. The researcher always remains an outsider, and the big issue is to overcome, or at least become aware of, your own cultural bias while attempting to understand the culture from the inside. The translation of cultural symbols from one culture into categories that will be meaningful to outsiders will always be imprecise. The problem is compounded since the cultural insiders may be unconscious of the underlying meanings of their own cultural categories. A basic problem with the scientific approach in an ethnographic research is that the cultural uniqueness of emic categories may be lost if they are forced into the observers etic categories in order to formulate cross-cultural generalizations.

According to Bodley (1994) and Geertz (2000a), a cultural theory describes recurrent patterns, but not necessary abstractions that can be generalized across cultures. Geertz (2000a) emphasizes that cultural theories have to stay grounded and only short flights of ratiocination tend to be effective. The point of a semiotic approach to culture is to gain access to the conceptual world in which the informants live and to be able to converse with the informants.

### Data analysis

The analysis of the empirical material aims at interpreting and understanding the meaning of actions carried out by patients, relatives, nurses and Hu Gongs. It aims at finding a hierarchy of meaningful structures describing the course of events. Geertz (2000a) describes “thick descriptions” of a cultural context, as when the researcher interprets and understands the meaning behind an action and is able to form it into a stratified hierarchy of meaningful structures.

The first step in analysing the collected data in this study is to read the transcribed material and recall the situations and the persons the author met during the data-collection. The next step in understanding and analyzing the material consists of clustering the collected material. The collected material in this study is written text which consists of field notes and transcribed material from discussions and conversation. This is clustered into cultural descriptors<sup>46</sup>. The cultural descriptors describe what the patients, relatives, Hu Gongs and nurses are doing. The patterns describe how they are doing what they are doing, and

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<sup>46</sup> The idea of formulating “culture care descriptors” is borrowed from Leuning et al.,(2002)

finally in themes the description of why they are doing what they are doing can be seen.

### ***Cultural care descriptors***

The cultural care descriptors are formed by information learned by the above described data collection strategies. The heading “cultural care descriptors” is used in congruence with the research questions concerning the cultural care practices, meanings, values and beliefs in caring for patients among both patients and nurses in Fujian province, PRC. Cultural care descriptors include several facts describing this topic covering practices, what the patient, relative and nurse are doing, the meaning of what they are doing and how they are acting. The schedule presented below shows an example of cultural care descriptors for patients and relatives, clustered according to the content of the material.

Table 2 below shows a piece of data collected sorted into “Culture care descriptors”. The culture care descriptors are extracted from the raw text material and compiled based on their content. They form the base for a “thick description” of the informant’s life at the hospital.

Cultural Care Descriptions, "What"	Cultural Care Patterns "How"	Themes "Why"
<p>The doctor shouldn't mention to the patient about a severe disease, the doctors should tell the relatives about it. Otherwise the patient cannot stand these news...The doctor tells the relatives and then they decide, the doctor tells the patient little by hand, step by step (patient).</p> <p>Because the patient must suffer from disease, if the patient is sad he must suffer a lot, suffer from the disease but he must be happy. It is important to be happy (nurse).</p> <p>I can see that the patient seems passive in the care, the relative is a "protector", protecting the patient from harm (observation).</p> <p>I want my relatives around and I feel better when they are around (patient).</p> <p>I can be at the hospital with my husband and then we both feel more secure. I want to be with him (relative).</p> <p>The nurses are in a hurry and I don't want to disturb them if not necessary (patient).</p> <p>The patient's relatives are sitting all over the ward, discussing with other patients' relatives, talking to each other. When he arrives to the ward, he is rolled in by two nurses and the relatives immediately start taking care of the patient, covering him with more blankets and the nurses checking blood pressure, emptying the urine bag and so on. The nurse is all the time educating the relatives about how and when to do things. Four relatives are standing beside the bed and two are coming and going (observation).</p>		

*Table 2. Cultural care descriptors*

### ***Patterns***

The next step is to answer the question "How are the informants doing what they are doing?" This forms patterns of actions. The patterns follow the descriptors, and become apparent as data is sorted into groupings of things which are similar. The patterns explain and make statements about how the cultural care descriptors are understood.

Cultural Care Descriptions, "What"	Cultural Care Patterns "How"	Themes "Why"
<p>Cultural Care descriptions "What"</p> <p>The doctor shouldn't mention to the patient about a severe disease, the doctors should tell the relatives about it. Otherwise the patient cannot stand these news...The doctor tells the relatives and then they decide, the doctor tells the patient little by hand, step by step (patient).</p> <p>Because the patient must suffer form disease, if the patient is sad he must suffer a lot, suffer from the disease but he must be happy. It is important to be happy (nurse).</p> <p>I can see that the patient seems passive in the care, the relative is a "protector", protecting the patient from harm (observation).</p> <p>I want my relatives around and I feel better when they are around (patient).</p> <p>I can be at the hospital with my husband and then we both feel more secure. I want to be with him (relative.)</p> <p>The nurses are in a hurry and I don't want to disturb them if not necessary(patient).</p> <p>The patient's relatives are sitting all over the ward, discussing with other patient's relatives, talking to each other. When he arrives to the ward, he is rolled in by two nurses, the relatives immediately start taking care of the patient, covering him with more blankets and the nurses checking blood pressure, emptying the urine bag a.s.o. The nurse is all the time educating the relatives about how and when to do things. Four relatives are standing beside the bed and two are coming and going (observation).</p>	<p>Protecting the patient from bad news is a generic care practice to alleviate suffering</p> <p>Taking over the bad news and carrying them until the patient is strong enough to get the news is a generic care practice intended to protect the patient from worries.</p> <p>The generic care practice to raise the patient's feeling of security, is conducted through being present and upholding the traditions.</p> <p>The relative's presence help the patient being well cared for. The relatives and the patient do not count on the nurses as carers. The relatives act as the voice of the patient.</p> <p>Generic care practice exists to assure the patient good care. The relatives taken an active part in the nursing care of the patient</p>	

Table 3. Cultural patterns



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Table 3 shows how patterns follow the culture care descriptors. The patterns are formed based on how the culture care descriptors are shown, and they form generic care practices.

### *Themes*

Spradley (1979) says that a cultural theme is any cognitive principle, tacit or explicit, which is recurrent in a number of domains and serves as a connection between subsystems of cultural meaning. Cultural themes are elements in the cognitive maps which make up a culture and which are larger units of thoughts. They consist of symbols which are linked into meaningful relationships. Cognitive principles will usually take the form of an assertion. A cognitive principle is something that people believe and accept as true and valid; it is a common assumption about the nature of their experience. Themes are assertions that have a higher degree of generality, but cultural themes need not apply to every symbolic system of a culture. Themes are general and abstract and they have intellectual and effective content which depends on intrinsic form rather than on narrative content. DeSantis and Ugarriza (2000) define a theme as an abstract entity that brings meaning and identity to a recurrent experience and its varying manifestations, which in this presentation are named patterns. A theme captures and unifies the nature or basis of the experience into a meaningful whole.

There are four criteria which form the basis of a theme: it should be based on data, abstract in nature, show a recurrence and the lowest level of data analysis from which themes can be identified is at the union of two or more categories (in this study it is patterns). Leininger (1985) emphasizes how the themes should emerge clearly from the data. Identification starts with identifying patterns and moves on to combining patterns into meaningful units. The process ends with a synthesizing of patterns into more holistic themes. These are extracted through a careful mental process of analyzing content from all data sources. The themes are the outcome of a creative and abstract thinking process, in which the researcher develops synthesised findings into themes, which support the raw or grounded data. The themes should clearly be seen in the raw data and be enlightened by quotations, in Geertz (2000a) words the theory has to stay close to the ground.

Table 4 shows themes which have emerged from the raw material. The themes are derived from the cultural care descriptors, which form cultural care patterns and finally themes.

Cultural Care Descriptions, "What"	Cultural Care Patterns "How"	Themes "Why"
<p>Cultural Care descriptions "What"</p> <p>The doctor shouldn't mention to the patient about a severe disease, the doctors should tell the relatives about it. Otherwise the patient cannot stand these news...The doctor tells the relatives and then they decide, the doctor tells the patient little by hand, step by step (patient).</p> <p>Because the patient must suffer form disease, if the patient is sad he must suffer a lot, suffer from the disease but he must be happy. It is important to be happy (nurse).</p> <p>I can see that the patient seems passive in the care, the relative is a "protector", protecting the patient from harm (observation).</p> <p>I want my relatives around and I feel better when they are around (patient).</p> <p>I can be at the hospital with my husband and then we both feel more secure. I want to be with him (relative).</p> <p>The nurses are in a hurry and I don't want to disturb them if not necessary(patient).</p> <p>The patient's relatives are sitting all over the ward, discussing with other patient's relatives, talking to each other. When he arrives to the ward, he is rolled in by two nurses, the relatives immediately start taking care of the patient, covering him with more blankets and the nurses checking blood pressure, emptying the urine bag a.s.o. The nurse is all the time educating the relatives about how and when to do things. Four relatives are standing beside the bed and two are coming and going (observation).</p>	<p>Protecting the patient from bad news is a generic care practice to alleviate suffering</p> <p>Taking over the bad news and carrying them until the patient is strong enough to get the news is a generic care practice intended to protect the patient from worries.</p> <p>The generic care practice to raise the patient's feeling of security, is conducted through being present and upholding the traditions.</p> <p>The relative's presence help the patient being well cared for. The relatives and the patient do not count on the nurses as carers. The relatives act as the voice of the patient.</p> <p>Generic care practice exists to assure the patient good care. The relatives taken an active part in the nursing care of the patient</p>	<p>Nonmalefience and protection</p> <p>Security and good care</p>

Table 4. Themes.

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## FINDINGS

### 10. Caring and suffering from a Chinese perspective

The study is carried out at three hospitals in Fujian province. The hospitals have different philosophies and all hospitals involved in the study are modern hospitals. They are linked to a university and act as a practice field for both doctors and nurses. Several nurses speak English at both hospitals. The hospitals are not compared to each other and no evaluation concerning the activity at the hospitals is made. The hospitals used for this study are university hospitals with many different specialities and with a large number of patients. The average duration of the patient at the hospital is 11 days; but the stay depends on the disease and level of wellbeing. The patients are from the Fujian province and the hospitals involved in the study have a large number of wards. The author has visited all of them several times, and chosen the hospitals as target areas for the study.

Fujian province is big with close to 35 million inhabitants. There are several cities in the province and the hospitals are linked to a university or to the government (e.g. the military hospital). People turn to the hospital whenever they are ill, if they can afford it. There is no system where doctors send patients to hospital and keep patients on waiting lists finally calling them in when they have time. The patients seek help when they need it. There is as yet no system with public health nurses or community health care, which takes care of minor health problems. The hospital is the place where all diseases are treated. All hospitals involved in this study, where observations and discussions, conversations with patients, relatives, nurses and Hu Gongs have taken place, have different standards of rooms depending on the patient's economical resources. If the patient can pay a higher fee, the room is more luxurious. At one of the hospitals there is an announcement appealing to wealthy people to donate money to the hospital. The donated money will be spent on patients that have no economic resources to pay for their treatments and hospitalization. The hospitals are crowded with people who are there for various reasons. To the author, a foreigner, used to limited numbers of visitors and limited number of people at a hospital, the environment initially seems very unfamiliar and confusing. Important questions, raised immediately when approaching the hospital, are the questions of suffering and health, curing, treatment and caring for the other. The patient has to pay for all treatments provided at the hospital, the medication, the food, the therapies and the bed.

During the stay in China the author learnt from the informants that formality and strict rules are a part of Chinese courtesy, and also a part of the world at the hospital. The concept “face” is important to understand to be able to avoid cultural pain, when communicating with the Chinese patient, family and nurses at the hospital. “Face” has to do with the image or credibility of the person you are communicating with. To insult, embarrass, shame, yell at or otherwise demean a person is never appropriate in Chinese culture. This phenomenon is called “to lose face”. Awareness of face and its’ impact is an important cultural issue. “Mianzi” (in English “face”) can be explained as status or self-respect in Chinese, and it is one of the worst things for a Chinese person “to lose face”. Commonly all criticism is given in private in order to protect a person from “losing face”. “To save face” is to avoid humiliation or embarrassment and preserve dignity. “Guanzi” (in English “good relations”) to other people are important for the Chinese and good social relations are a symbol of personal ability and influence. Someone who has no connections is despised and only half a person. “Keqi” (in English “politeness”) is important and it is very impolite to be arrogant. Humility and modesty are virtues which are appreciated.

## **The structure of the presentation**

According to Geertz (2000a), the essay is the natural genre in which to present cultural interpretations. The result of this study is presented in a modified essay form<sup>47</sup> which gives a personal touch to the presentation. The presentation consists of three different subchapters. The first subchapter describes the patients’, relatives’ and Hu Gongs’ life in hospital, the cultural care descriptors, forming patterns and themes, which describe the generic care practices, meanings, values and beliefs about care, caring and the experience and expression of suffering. Presenting the hospital and the people at the hospital shows glimpses of daily life, who the people at the hospital are, what they are doing and why. The daily life is elucidated with quotations of observations and discussions, and the language in the quotations presented is not corrected, it is as it was said and observed. The second subchapter describes the nurses in the hospital following the same model as the first subchapter. The presentation continues with the third subchapter presenting the social structure’s influence on suffering and caring. This in turn reveals patterns of interpretations which are related to each other and open up an understanding for how suffering and caring are experienced, expressed, interpreted and understood among patients, relatives and nurses in a Chinese context.

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<sup>47</sup> The presentation follows the form commonly used when presenting scientific research with the different phases in a research process separated. In an essay the different phases of a research process are not clearly separable.

## **The patients', relatives' and Hu Gongs' voice – practices, values and beliefs concerning suffering and caring in a Chinese setting**

Where to start, when trying to interpret and understand abstract concepts like suffering and caring in a foreign culture? Following Geertz (2000a) the first question to be answered is “what do the people do?” When trying to understand suffering the question is “In what way is suffering understood among sufferers (in this study mainly patients)”, and “what caring practices can be seen in alleviating suffering”? Language can be a key and offer guidance for how a phenomenon is understood in a culture. In China people use different words and combinations of words to describe situations in which an individual experiences pain, difficulty or hurt. How are situations, similar to those called suffering in a Western culture, described in China? The words used to describe suffering can help to understand how it is experienced, expressed, interpreted and understood in a culture. Each culture gives its own words to important phenomena. The understanding of the words describing suffering is based on discussions with patients, nurses and relatives.

In Chinese, suffering is described with several words which have different meanings. Informants participating in the study describe situations similar to what we in Western culture would call suffering as following: there are three Chinese words or signs for suffering, “tòng” “ku”, and “téng”. Tòng is generally used to express aches; pains; sorrow and psychological pain. People may say “I live a suffering life” because of loneliness (tòng ku or ku) or economic problems (ku), and it can be translated as suffering due to social circumstances. “Téng tòng” mainly means physical pain such as aches, cramps pains or soreness. When one gets injured one can say it is very painful and then use téng tòng, but “tòng” can also describe pain in the sense of spiritual or psychological suffering. “Tòng Ku” means pain; physical or social suffering (for example, when one is suffering from cancer pain or postoperative pain or from loss of a loved one) it is also explained as suffering and a painful experience. “Tòng” can mean both physical and spiritual pain and suffering. “Ku” can also describe spiritual suffering. Depending on the combination of the words the experience is described. “Hen Téng” is used when the suffering is very obvious and painful while “Kong Tu” is used if the patient is scared of a situation which leads to suffering (e.g. scared of a diagnosis). “Jue Wang” is used as an explanation of hopeless situations. “Bing” is used when describing illness, becoming ill and “zhèng” when describing a disease.

What do patients and relatives do to avoid and alleviate suffering? And how do

they do what they do? What meaning do they ascribe their actions? Based on the above the informants give words for suffering due to social circumstances (such as economy and loneliness), spiritual suffering, psychological and physical suffering and suffering when the situation is hopeless (interpreted as existential suffering). Suffering due to grief and loss are also mentioned. There are different words used for disease and suffering which can be understood as affirming the belief that suffering can be present without disease, since they are not one and the same thing. The informants describe several instances of suffering in which a disease is not a part of the situation.

Below the various themes emerging from the data concerning patients and relatives and their experience and expression of suffering, as well as the tenets in generic care aiming at alleviating the patients suffering will be presented. The various themes emerging from the cultural care descriptors are presented as subheadings, the patterns are in bold letters and the quotations are original from the field diary or from the discussions. The subchapter ends with a description of how the patients' and relatives' values, practices, meanings and beliefs concerning suffering and caring can be interpreted in relation to the different themes and patterns.

The themes presented are as follows; connectedness – not being abandoned, integrity and privacy in a crowded room, nonmaleficence and protection, security – being assured good care, trust –relying on relatives and doctors and finally harmony – the ultimate goal. The themes are the values which evidently dominate the patient's life at hospital and which answer the question of why people act as they do. Patterns are presented within the themes, and have no internal ranking although numbered. The patterns form practices and the themes and patterns form the beliefs that undergird actions and reactions in caring for the suffering human being seen from a cultural context perspective. The cultural descriptors are marked by the use of bold letters.

### ***Connectedness – not being abandoned***

The first thing that strikes me when I enter the hospital milieu is how crowded it is. There are so many people that seem to belong to the hospital. There are patients, sitting at the outdoor clinics waiting for injections, consulting with the doctor, waiting for an x-ray or for medication. They seem to never be there alone, there are always one or several family members around. Some of the patients show their suffering through facial expression or body language, which is similar to what I am used to in a Western culture. I can see the facial expression and body language of a patient who is suffering, but also the anxiety seen

in facial expression and body language of the mother or father sitting with their sick child on their lap - it must be the same all over the world.

There is also the boy or girl, dressed in a hospital uniform, responsible for the elevator, helping relatives, families and visitors to the right place, helping staff to get into the elevator and out again. There are the women who guard the wards, and are responsible for not letting visitors in at the time for the doctors' round. There are the "Hu Gongs" and the staff consisting of various kinds of doctors and nurses. There are the pharmacists, the kitchen staff, the boy bringing water to the wards and the cleaners. Everywhere there are people hurrying from one place to another.

There are patients in the wards sitting or lying in their beds and there are relatives, families and friends in the patients' rooms. The rooms in the wards are crowded with people and all over I can see different categories of staff. Many of the wards are big, with up to 50 beds, and the rooms are differently equipped depending on the rate being paid. There are smaller rooms as well for two – three patients or single rooms. All rooms have beds and bedside tables beside the beds. At some wards there is space enough for relatives staying overnight while other rooms seem so crowded with beds and tables that I can hardly imagine how extra beds fit in, and many relatives do not even sleep in extra beds, they sit in the chair beside the patient. There are rooms more like hotel rooms (expensive) and rooms with 8 or 10 beds, with no luxuries (less expensive).

During a walk in the hospital area (regardless which of the hospitals I go to) I can see the operation theatre, where relatives are waiting outside, anxious to get to know how the surgery has succeeded for the sick relative, all of them getting up on their feet whenever a patient is rolled on the bed through the operation theatre's doors, on the way to the bed ward. I can also see people who are waiting outside the elevator for the patient to be rolled out. It is crowded and there is noise, the air is filled with questions and anxiety.

*...if the patient is undergoing a surgery... the relatives ask how it is going... They are waiting outside the operating theatre... they just want to see the patient and they are very upset. (Nurse.)*

The anxiety about the outcome of a surgical procedure is obvious. It can be seen as fear of the unknown, or simply anxiety for a loved one who is ill. There are relatives walking around talking to each other, waiting for something, like

the outcome of a surgery or an examination, outside the hospital. There are relatives coming and going with food for their hospitalized sick relatives - people everywhere. Commonly the relatives bring the patient food, the patients do not often use the hospital kitchen. Chinese people generally follow a special diet for gaining health, and this is linked to the old belief in TCM. The special diet is important but to support the patient and to avoid extra costs for the hospital food is equally important.

Below an outline of how connectedness and not abandoning a sick family member are seen in a Chinese setting is presented. The generic care practices which aim at not abandoning a sick family member are also discussed. The following patterns were seen describing the value of connectedness;

1. Visiting and staying at the bedside is a generic care practice to keep the patient connected to the family and daily life outside the hospital.
2. Bringing the home to the hospital is a generic care practice aiming at keeping the sick family member connected to the family.
3. Hiring a Hu Gong when the relative cannot be present is a generic care practice aiming at not abandoning the sick family member.

**Visiting and staying at the bedside is a generic care practice.**

There are different ways of showing concern for a sick family member, friend or colleague. Two different situations will be described below, throwing light on the generic care practices used to keep the patient connected to the family and daily life outside the hospital. Concern for the patient can be shown both on a superficial level by “showing up” (friends, colleagues) and on a deeper level when the concern is about a loved family member or a dear friend. The deeper form of concern is rooted in the longing for wholeness, the desire not to let the family become split, to stay connected.

There are generally relatives, family members and other visitors in the ward surrounding the bed, the patient is not alone. This is the first sign of connectedness at the hospitals where I have conducted the data collection. The relatives sit at the bedside while the patient is awake or sleeping and also stay at the bedside during the night at many of the wards I visited.

The patient’s and relatives are influenced by the doctors’ and nurses’ opinion of how the visiting hours should be arranged, and this influences on the patients’ possibilities to stay connected to the family. Many of the doctors and nurses I



have met, have an education or have had a practice period abroad. They have been to South Africa, Japan, USA or Europe (England). They have seen hospital systems which differ from the Chinese system, and they make comparisons with different systems when discussing the Chinese system. The amount of people coming and going at the hospitals is seen as an obstacle for doctors and nurses, and from their view also for patients, since, according to the doctors' and nurses', the patients cannot get rest having so many people around. The doctors and nurses are concerned about the risk of infections and the inconvenience that the amount of visitors causes to the patients. The relatives disturb the nurses and the doctors with questions which require answers. The personnel at the hospital also know that the visitors are not always there because of their desire to care for the patient. They are also there for their own sake, it is a social pattern to show concern in public. To "show up" is to be present, and to spend time with a patient is a way of connecting the sick person to life outside the hospital, not to leave a sick person alone. It is also a form of confirming the sick person as being a patient and in need of attendance. To "show up" is also a part of the social life, for example when you visit your boss, your colleague, and it can benefit the visitor himself socially to "show up". To have no visitors is a sign of having no value.

Although the doctors and nurses find it difficult to have large amounts of people around, they also appreciate being cared for by their own relatives when they are sick. Their concern for infections and the patient's lack of rest slips into the background when they put themselves in the patient's situation. To be cared for by relatives is to be connected to the family and also to know that the family is concerned about the sick family member. Below is a quotation from a doctor that shows the doctors' (and also nurses') opinion of the connectedness to the family and the large amount of visitors. The cultural care descriptors are in bold letters and they describe the dual expectations on relatives and visitors at the hospital.

***I am a doctor and I don't like all the relatives hanging around at the hospital. They are not giving the patient peace and calm and the patient cannot rest. They are also disturbing the nurses and doctors and sometimes they are there not because of the patients need but because of their own need. You need to show to your boss that you consider about him, and then you visit him, but you don't really care about him, it is like a game. But if I get ill I want my relatives around otherwise I will feel lonely, and I don't want the nurses to take care of my personal hygiene. (Doctor.)***

The nurses in the study have similar thoughts about the numbers of visitors at a ward and also same thoughts about wanting to be cared for by their own relatives when sick. The doctor quoted above is one of those who have been to the USA. He likes the system with few visitors, visiting hours, and not so many relatives who want to ask the doctor and nurse about a patient's condition (and also other questions). Nevertheless, he cannot imagine giving up the system of having relatives around since if he was a patient, he would feel insecure in having strangers helping with personal hygiene; to be cared for, and get personal care. To be cared for and get help with personal hygiene by somebody who cares (a family member, not a stranger such as a nurse) is also a sign of the family confirming the sick patient as a patient in need of care.

To be lonely is considered as to be abandoned, and nobody is expected to be alone at hospital. It is also a matter of concern and responsibility. It is a responsibility for the relatives to care for the sick family member. So although the doctor quoted above is a doctor, he can put himself in the patient's situation and understands that the relatives have an important part in caring for the sick family member, giving attention and confirming the role of a patient in need of care. Generic care fills the purpose of removing feelings of loneliness and abandonment by engaging in visiting and caring for the patient.

To be confirmed as a patient gives the sick family member the role of someone who needs to be cared for. The generic care practices consist of not leaving the patient, keeping him or her close to the family and to friends. This keeps the connection alive. Not leaving a sick person alone is also linked to "showing up", showing your consideration for a person although not really caring for him or her. "Showing up" is a part of the social life and the social expectations. Although the doctor quoted above, says that visiting customs are like a game, "you do not concern, but you show up", visiting is nonetheless significant. It is a part of the social life and a sign of value to have many visitors. If nobody "shows up" it means that the patient is not highly valued. The more people that "show up" the higher valued the person is. Confirming the patient as a sick family member by visiting him or her is a part of the social norms which aim at giving a patient a feeling of being connected to life outside the hospital.

### **Bringing the home to the hospital is a generic care practice.**

By spending time at hospital I learned that one way of caring for another is to spend time and be with the other, not to abandon a sick relative. To be left alone raise a feeling of abandonment. This becomes understandable when one learns that a person in China has to be connected to others in order to feel belonging. There are visiting hours at the hospital but they are not followed.

The routine of visiting hours is a new one, and it has not been accepted by visitors. The hospital is not a place where relatives visit the sick family member. It is a place where the relatives, under guidance of professional nurses, take care of their sick family member. Being present is a way of caring for each other. Presence is also a way of showing the sick family member's belonging to the family. Suffering from loneliness is a suffering initiated by social circumstances, and nobody should be left alone.

One of the nurses acting as an informant in this study says that it is unusual that the patient does not have visitors. A lack of visitors can indicate economical problems (there is nobody who will pay the hospital bill), but also being abandoned by the family for other reasons. One of the patients I met was an old military man. He suffered from dementia: he was agitated, aggressive and difficult to take care of. I met him at the Intensive Care Unit (ICU). He was lying in bed in a room intended for patients who need to be isolated because of (risk of) infection or other reasons. The man was not in need of intensive care, but it was the only place where the hospital could provide him with a bed. He had no visitors. His son did not want to care of him since he was disoriented and difficult to handle. They had hired several *Hu Gongs* but nobody wanted to be with him for longer periods. Now he was at the ICU where they could take care of his personal hygiene and also give him medical treatment for his heart problems. At the intensive care unit there are health care workers, without health care education, who take care of the personal hygiene of the patient together with the nurse. The old man was just lying in the bed, talking loudly and sometimes screaming. His hospitalization was paid by the government so there was no problem with costs, although he was in an intensive care unit. He was nevertheless abandoned by his family. The old man's situation shows one of the problems of China today. There is a need to create solutions for how to care for elderly people who cannot take care of themselves and who have no family to rely on. The solution has to be in accordance with the cultural values a solution functioning well in a Western culture might not function in China. According to the nurse a patient is seldom abandoned, but this might occur when the "one-child policy" has changed society and the cultural values of connectedness and belonging to the family.

Home and the family are important institutions for the Chinese patient (and for other Chinese people as well). The young family gets support from the elder family members and the elder family members from the younger ones when needed. The relatives stay in the hospital with the sick family member, and they take turns to be there. The following extract is from the field notes which describe a situation where the relative takes care of a patient. The location was

the intensive care unit and there was limited time for the relatives to visit the patient. In addition, there was certainly not any space making the environment feel like a home although this was what the relatives did. The visitors were allowed to stay for half an hour, but in special cases they could stay for a longer period. The intensive care is an open space with curtains between the beds for privacy. Some of the generic care practices aim at to normalize the hospitalization in the attempt to show concern and alleviate suffering. This kind of attempt is written in bold letters in following quotation.

*There is this old man, 80+. He seems to have been a large man, but now he is thin. His wife is a short chubby woman dressed in dark coloured clothes, as the traditions decrees. The man is lying in his bed, he has pyjamas on and he is not capable of walking anymore. The man is coughing and his wife is helping him. I try to help him when he is coughing by changing his position in bed. The wife looks at me, and smiles. I ask him (through my co-researcher) how he feels today and he answers that it's getting better. I went out for a break (lunch) and when I come back he smiled at me like he saw an old friend. His wife is still there and she gets him some new warm water. She helps her husband to drink the water by supporting him when he tries to sit up in the bed. **She is making the environment comfortable for him, moving, washing his cup, covering his throat, holding his hand.** It is so touching to watch the old couple, the man is lying in the bed, with no possibility to move and the wife is all the time around him. **When he sleeps she is sitting beside him just watching. She is like a maid and wife at the intensive care unit.** When it is time for the wife to go she packs her bags and then she goes to the door. The man is sitting in the bed and I can see by his facial expression that he feels like half of a unit, his eyes are watching the door like he was wishing his wife to come back, there is loneliness in his eyes, and then she comes in again and a big smile appears on the mans face, she is again cleaning some cup, correcting the scarf around the man's chest and waves goodbye. The man is left alone and I can see him longing for her. (Observation.)*

This extract from the field notes shows the relationship between a patient and a relative. The wife is making the environment comfortable and home-like. She is sitting beside him watching him sleep. The patient feels good having his wife beside him and the wife also wants to be near her husband. The wife is serving the patient with water, homemade food, and is covering his throat with a scarf from home. Through small gestures she makes the ward more like at

home, washing cups, serving him tea. She is not like a visitor; she belongs to the ward, to be at the bedside. This belonging or connectedness is important for the patient. It is possible to uphold the connectedness to the family and home in a hospital as well. The generic care practice which aims at showing connectedness consists of creating a homelike situation in the hospital.

Another situation totally different from the above mentioned also describes the generic care practice that moves the home to the hospital and makes it homelike. The case concerns a sick child and generic care practices to give the child and the relatives (parents) a feeling of being connected as a family, and to daily life. To move the home to the hospital is a way of normalizing a difficult situation, to momentarily forget the most difficult of all, a sick child in a terminal stage of cancer. The observations were conducted at a tumour ward and the patient was a young boy with a severe disease. The generic care practices, aiming to show concern and through this alleviate suffering are in bold letters.

*His father is here with him and soon his mother comes with food. **They eat together.** The prognosis for the boy is not good, but it is not discussed, the nurses do not support the parents by talking to them, they just come in for nursing procedures. The boy has IV infusion, supportive. His appetite has decreased and he doesn't want to eat anything. He has metastasis in the bones and in the lung. He is given a lot of infusion before and after chemotherapy to prevent his kidneys from getting damaged and for unexpected side effects of the medication. **His mother is sitting beside him,** I can see by her body language and her facial expression that she is unhappy. Her shoulders and neck are slouching. This could be because of her tiredness since she is all the time at the hospital. The boy is just lying in the bed, doesn't want to play anymore, just lies watching TV. His mother is helping him with everything. She is helping him to urinate and uses a bottle, just an ordinary water bottle, not a bottle specially designed for urinating in bed. The boy is just lying on his back.*

***Mother and son are talking to each other;** the mother is all the time showing her concern. **She is touching her boy all the time, like she had a need to confirm that he is there and also to confirm to the boy that "I am here"**. I can see fear and anxiousness in her eyes and her body language. **The boy is never left alone at the hospital; the parents are there 24 hours/day.** The mother has given up her job and they spend all their money on getting the boy healthy. He has been a patient of this ward for half a year by now. He has been at home*

*for short periods during this time. **Yesterday evening I could see his mother sleeping in the same bed with the boy lying beside him.** This can be because she wants to be close to the boy but it can also be because no extra bed fits into the room.*

***The mother is touching the boy all the time she is touching his hair, his arm his shoulder, changing his position to the better in the bed.** Now his father arrives and the boy sees him and he smiles and **makes some jokes with him.** The mother seems tired; every time the boy coughs she is worried. She is looking at him when he coughs, bending forward ready to help.*

*Both mother and father know about the disease and the risk is obvious that the boy not will recover, not survive. The boy is old enough to understand. The nurses don't talk about this fact with the parents, but the doctor has told them. **Nobody actually talks about death with them, it is a family matter.***

***The boy is smiling at his mother, talking about something on the television; they are watching the same movie and seem to like it.** The mother is all the time focused on the boy, the IV infusion, holding his hand, correcting his clothes, watching the IV, holding his hand, pressing the bell to get a nurse to change the infusion bottle. The infusion is changed and a new bottle starts running. The boy and his mother are talking to each other; his mother show her son that she cares for him **and the he makes a joke with Mummy.** (Observation.)*

When a patient is seriously ill, there is always some degree of existential suffering. The family surrounds the sick person to show love and concern. The existential suffering can be seen in situations where the patient's prognosis gives no hope for the future. Parents' suffering when a child is seriously ill may be similar all over the world, but the expressions of the suffering might differ depending on culture. There are different generic care practices with which the family tries to alleviate existential suffering, such as spending time together, and do normal things done in a home like watching TV, and joking with each other. These are generic care practices aiming to ease the situation for all counterparties.

In the situation described above the fear and anxiety involved in losing a son is obvious, as well as the need for touching him and keeping him there with the

family. The parents are trying to normalize the situation; to be able to forget reality for a while by eating together, watching TV together, making jokes and being close to each other. This happens in a traditional ward in a patient room at the hospital where the boy shares his room with an old man who has a Hu Gong beside him. Everything is open for everybody who wants to see a member of the family.

The tension is visible and the fear is on the surface. The situation is a family matter; the family gather round the boy and form a ring of support. The boy is not abandoned, since he is never left alone. The parents give up their own life to take care of a sick child, and it affects the family's economical and social situation. A child is taken care of by parents. The family has to support itself; the hospital is not providing any support for the family in this difficult situation. The family has grandparents supporting them financially, but it is obvious that the difficult situation they are going through is their own.

**Hiring a Hu Gong when no relative can be present is a generic care practice.**

At hospitals in a Chinese setting it is expected that the relatives stay with the sick patient to care for his/her basic needs. However, it is not always possible to find a relative that can give up their job and stay with the patient at the hospital. This creates a tension between the younger generation and the elder generation. During my stay at the rehabilitation ward, I learned to know an old man who told me about the importance of having a family member at the ward during hospitalization. One of the family member's important tasks was to keep the sick family member close to the family and in a good mood. He could not see any problems with having a family member at the hospital. He said:

*...it is only one who has to give up the job. (Patient.)*

By saying that it is only one who has to give up the job he placed the importance of taking care of the sick family member ahead of keeping a job and through this he shows the security in belonging to a family. A person could give up a job and take care of a sick family member and count on the family's support after hospitalization. Nonetheless, because of these changes, a special group of staff named "Hu Gong" is present.

The Hu Gong is employed by the patient or the patient's family to take care of the sick person either during night time, daytime or round the clock. One important task for the Hu Gong is to keep the patient company and in a good mood, just as a relative would. The Hu Gongs can be hired for a longer or a shorter period, from weeks to years. The care involves everything from basic

nursing care (help with food, nutrition, personal hygiene, toilet), to co-operation with nurses and doctors regarding different medical treatments (such as IV infusions and therapies). The Hu Gongs have no special uniform, they wear their own clothes. There is nothing that indicates that they are hired relatives, they act and look like relatives of patients. The following quotation is an extract from the field notes, describing a situation where the Hu Gong is in action. The Hu Gong's tasks as they are observed are in bold letters.

*A Hu Gong is accompanying him (the patient) and the Hu Gong is **helping him to go to the toilet, and to press the alarm when the IV infusion bottle is empty.** When the patient wants to go to toilet he is there to help him, he is supporting him when he is walking and holding the IV bottle in the other hand. **Both of the men are watching TV, and they are laughing at the same things.** It is a big difference in age between the men and I can imagine it is difficult to find something in common to discuss, but the **Hu Gong shows a caring attitude, seems to be alert to the old mans needs.** The Hu Gong is **correcting the pillows in the bed, watching TV laughing together with the patient.** **The patient fall asleep and the Hu Gong is sitting beside him while he is sleeping, watching TV, monitoring the IV drip.** (Observation.)*

The Hu Gong supports the patient with personal hygiene and toilet matters, entertains the patient, spends time with him and cares for him. The Hu Gong is not trained to monitor medication, but I only saw this task carried out by the relatives or the Hu Gongs, the nurses relied on the relatives and Hu Gongs or the patient in being capable to monitor IV infusions for example. The Hu Gong has no formal training in nursing but his or her task is to take care of the patient instead of a relative. The Hu Gong shows a caring attitude by being observant to the patient's need for care. The Hu Gongs are commonly from rural areas and are poor people who move in to bigger cities to improve their economic situation.

The co-operation between nurses and Hu Gongs does not work well in every hospital. A nurse said "you can always ask the cleaner, they know where to find the Hu Gongs, or just ask around". On other wards and hospitals there are lists for the patients with names of Hu Gongs available for hire. One patient said that the Hu Gongs are recommended by other patients. They get the name of a good Hu Gong from other patients at the ward who already have a Hu Gong. The hospitals carry no responsibility for educating the Hu Gongs, neither do the hospitals officially accept the system with Hu Gongs. At one of the hospitals in this study the Hu Gong said that they get 1 week of introduction before they start working, but it was unclear who organized the education,



and the education was not recognized by nurses. One of the Hu Gongs I talked to had been hired by the same lady for one year. She was hired 24 hours/day and 12 months/year. She stayed at the hospital with the lady and helped her with everything. Her husband was also a Hu Gong and he lived with another patient and they seldom met. The Hu Gongs have to satisfy the patient since they are totally dependent on the patient's goodwill to get good recommendations for further jobs. The reason for choosing to be a Hu Gong was, due to the informants, because of money and because of the joy of being able to help somebody. One of the Hu Gongs also mentioned the fact that he was learning a lot, and that he could use the gained knowledge when he visited his home village. The knowledge was in the field of nursing and medical treatment.

According to the Hu Gong informants, the patient's physical and mental care is very important. The Hu Gong has to make the patient happy and support the patient in all treatments and therapies prescribed by the doctor. The Hu Gong must stay at the bedside until she or he is allowed to go out, and the details regarding working times differ from case to case. The following extract is from a discussion with a patient who outlines the tasks of a Hu Gong, which are written with bold letters.

*The **Hu Gong's task is to observe the patient, to watch the IV drip and to help to the toilet and to help the patient to eat and drink water. The worker should be a company to the patient that is a part of her job.** The patient and the Hu Gong should be able to talk to each other. **The patient should also care for the Hu Gong, let her go out for dinner.** The Hu Gong and the patient must be able to communicate and have a good relation. **The Hu Gong should be like having a daughter here. Some Hu Gong s are like daughters.** The Hu Gong is chosen by the patient based on interview. The nurses in China never do basic nursing and therefore we need Hu Gongs. The number of patients is too much and there is a shortage of nurses. The system of the hospital makes it impossible to keep so many nurses. In China there are so many people and to be a worker is to have a job, like others, it is a Chinese tradition to have workers. (Patient.)*

The tasks for a Hu Gong include monitoring the IV drip, helping with personal hygiene, keeping company and acting as a relative. The patient also has to care for the Hu Gong. The Hu Gong moves into the patient's room at the hospital and he or she follows the patient all day. They are only allowed to leave when they get permission. The patient's relatives visit the sick family member but they do not stay over night or during day time.

The Hu Gongs work as substitutes for relatives and an important part of their job is to act as a relative. The generic care practices which aim at not rising the feeling of abandonment consist of hiring a Hu Gong instead of leaving the patient alone. The relative buys a connectedness to the family, by hiring the Hu Gong. The informant quoted above, continued by telling me who the Hu Gong was, what they did and what the difference was between the nurse and the Hu Gong. The culture care descriptors are written with bold letters.

*Almost all Hu Gongs come from poor economical areas and **they do the simple things and the nurses do the more specialized job.** It is different in China the level between the nurse, doctor and Hu Gong. The Hu Gong do the simply things and **they have no good background and education and the nurse must go to school and graduate from the nursing university and they earn more money.** About the 24 hours work, I let the worker go out for breakfast, lunch and dinner and she can have a rest when she need. **In the evening when the patient sleep she also can sleep so it is not work for 24 hours** [but the Hu Gong sleeps in the same room as the patient]. The Hu Gong come from a poor area and has no possibility to get another job, **if she gets a better job she will take it, she can go out and find a better job.** The **Hu Gongs job has a very low value.** Normally Hu Gongs basic nursing is not so good and the salary and the value is not so good. **Everybody in the society is equal and if you do a good job you will get respect if the do bad job nobody respect you.** (Patient.)*

Although the Hu Gong does not have any formal education, he or she is given the responsibility to supervise medical treatments such as IV medication, follow up doctor's prescriptions and assist the patient with basic physical needs. The Hu Gong has to be a multi-talented person, and he or she is given little credit for his her skills. The nurses do not value the Hu Gongs very highly, neither do the relatives. However, according to Hu Gongs I have talked to, and based on observation, they co-operate well with doctors, nurses and patients<sup>48</sup>. It is a contradictory situation the relatives cannot abandon the sick relative and when it not is possible for the relative to stay at the bedside, they hire a Hu Gong as mentioned earlier. It is considered highly valued to not abandon a sick relative, but the Hu Gongs does not have a high value although replacing a relative, since the Hu Gong is seen as a maid or servant by some of the patients

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<sup>48</sup> This might be a misinterpretation since the number of Hu Gongs acting as informants in this study is limited.

and nurses participating in this study although several of the informants in the study emphasized the respect for the other's job. The Hu Gongs I discussed with are proud of their job and think it is important, this is also verified by the observations and field notes. The job is carried out with love for the patient. The Hu Gongs do not have the possibility to have a rich social life, and therefore patient becomes their family.

There are both female and male Hu Gongs, since a male Hu Gong can only work with a male patient and a female Hu Gong can only work with a female patient. I saw an exception, where a couple (husband and wife) were hired to take care of a woman suffering from hemiplegia. The couple lived together with the lady at the hospital and had done so for the last year. The lady had a room of her own on the rehabilitation ward. The Hu Gongs had decorated the room like a home. The lady was from Taiwan and her son has hired the Hu Gongs to take care of her, since it was too long a distance to travel between Taiwan and the hospital where the mother was cared for. The hospital provided the Hu Gongs with beds.

The nurses do not invite Hu Gongs for co-operation actually the nurses do not always like having the Hu Gongs at the ward except for at the ICU. They appreciate the Hu Gongs' work with basic nursing care, since the nurses think basic nursing care is not "fancy"<sup>49</sup> and they "get tired" of it, but also feel like there are too many people involved in the care for patients, which makes the nursing care difficult to control. In situations in which I could observe the doctors treating the patients I could see that the doctors involved the Hu Gong in the care the same way as they did with relatives. The Hu Gong has no ethical code for his or her work like the nurses have. The Hu Gongs can discuss their patient with others, but according to the Hu Gongs they never do it since such a violation of the patient's dignity might obstruct further job possibilities as Hu Gongs. To hire a Hu Gong is a generic care practice. It is a way to avoid abandoning a sick family member and to keep a connectedness to the family although the Hu Gong is a replaced relative.

### ***Integrity and privacy in a crowded room***

Chinese people, like most of us, do not want to expose themselves to strangers. Discussions with patients and relatives indicate that exposition can be physical or mental. The physical exposition is described as showing the body. The female should not show their breasts or genital organs to strangers and

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<sup>49</sup> The word "fancy" was used by one of the nurses participating in this study, when describing why it is not popular to carry out basic nursing care.

men should not expose her genital organs. The mental exposition concerns emotions and family matters. Emotions should not be shown to strangers but should be kept inside or shown to the close family. Family matters should also be kept within the family. Facial expressions can nevertheless be interpreted and understood by a stranger and/or foreigner who consequently can recognize sorrow, pain and anxiety.

One of the common generic care practices among the people I have met is to keep the family tight, to let the sick family member be a natural part of the family and through this avoid the mental exposition of a sick family member. Most of the patients I have met are taken care of by their relatives (or Hu Gongs), except for those who are isolated or those who need highly specialized nursing care. One of the families' tasks is to uphold integrity and privacy although the hospital is a very crowded place. There are various ways of upholding integrity. One is to involve family members only in personal matters. Another strategy is to only involve family members in the basic care.

A large amount of people are coming and going at the hospitals. People stop by and show curiosity by listening to and watching what is going on in other patients' rooms. This takes place when doors are open, or when doctors meet patients and discuss matters concerning disease and treatment in corridors, or in a room where there are other patients and/or relatives. It is difficult to maintain the integrity of the patient. Not being exposed is important, but it is paradoxically equally accepted to be curious. Integrity and privacy are difficult to uphold since the hospital is so crowded, and since it is accepted that strangers stop by and listen.

The patients, nurses and Hu Gongs clarify that the Hu Gongs have no professional ethical code to follow regarding caring for the patient and they are a big group at the hospitals. The Hu Gongs have possibilities to discuss even the most private matters concerning a patient with other Hu Gongs, or people outside the hospital. When asking if they do so, one Hu Gong answered that they learned how to handle patients by discussing situations with each other. By hiring a Hu Gong, the patient does not buy integrity.

The lack of room at the hospital makes it difficult to uphold privacy and integrity. The hospital is like a crowded room. Below I will outline how integrity and privacy are seen and how this is linked to the values that dictate patients' and relatives' practices, meanings and beliefs concerning caring and suffering.

The following patterns were seen as displaying the value of integrity and privacy:

1. Insuring that the patient is not emotionally exposed is a generic care practice.
2. Insuring that the patient is not physically exposed is a generic care practice.

The different patterns are outlined below and further clarified by quotations from the patients and relatives.

**Insuring that the patient is not emotionally exposed is a generic care practice.**

People I have met in China do not openly express their feelings, rather the opposite – it takes time to learn to know people. The Chinese people I have met are reticent, not showing their emotions openly. Many important things are said without words. Non-verbal language is widely used, and these small signs are usually not understood by a foreigner.

One of the important things expressed by the patients at the hospital is the wish not to be exposed. The need for integrity and privacy at the hospital is seen in peoples' shyness about exposing themselves. Because of the amount of people at the hospital it is difficult to arrange privacy for the patients. When privacy is not arranged integrity can be violated. When asking nurses about this, they admit that the hospital is crowded and that it is difficult to create privacy for patients. It is possible to use curtains, if the patient room has this facility, but few patient rooms I saw had it. During observations I found that people do not talk so much although a relative is present. The "doing" was more prevalent than "talking" in caring for the sick relative.

Chinese people do not want to show their anxiety, weakness or grief in public, and they are not expected to do this since it would expose the person too much and consequently embarrass people around. The nurses are not prepared to handle situations when emotions are shown this embarrasses them as well as the patient, which makes a difficult situation even more difficult. To avoid these situations is also to avoid increased suffering. The patients and relatives create their own privacy by not discussing openly and in not showing emotions even though the suffering can be seen as existential. During my stay at the hospitals I observed a situation where a relative burst into tears in front of nurses and in front of me. This created a situation that was difficult to handle. The emotional suffering was not controlled and the nurse had no tools or methods

to help the woman handle the situation. The crying woman was left alone to get control over her feelings by herself; there was no comfort by touch or words by the nurse in that situation. However the nurse told me that afterwards when the woman has calmed down they would discuss the situation. This situation was difficult for both the nurses and the woman who was crying.

It is not appropriate to share feelings with people you do not know and by having relatives at the ward they can act as discussion partners but it is difficult to find a private space where discussions can be held. It is nevertheless appropriate to show anxiety when waiting outside the operation theatre or when approaching a doctor or a nurse with questions regarding treatment. It seems like some feelings in certain situations are appropriate to show but generally it is not expected that patients show emotions in hospital, especially not to strangers. Integrity is linked to suffering in public and to suffer emotionally damages the integrity.

Insuring that the patient is not physically exposed is a generic care practice. A social norm is to show concern by visiting a patient. Almost all patients have a large amount of visitors and this gives the patient the feeling of not being left alone and also of being in focus. However, it makes the hospitals crowded. Since it is a cultural pattern to show concern by visiting patients, it is difficult to limit the numbers of visitors at the wards. To have a big number of visitors at each patient's bed makes it difficult for the individual patient to uphold a private space, but this is accepted by the patients I have met. The rooms are crowded with people, and relatives stay with the patient day and night.

The patients I met did not complain about the amount of visitors. They did not even complain about having to meet the doctor in a room filled with other patients. Several times I could see doctors creating a space in a corridor or at a ward beside the beds, where the doctor could see patients and discuss with them or with relatives. The doctor could make examinations and have discussions with patients, and other patient's relatives stopped by and listened. It is also accepted that the doctor or the nurse cannot create a private space where discussions, treatments and examinations can be carried out even though it is not acceptable to be exposed.

Physical exposition is to expose the body for other people. The relative is there to help the patient to avoid exposing their body to strangers. The relatives take care of the patient's personal hygiene; the patient is washed in bed (if the condition does not allow the patient to independently take care of his/her own hygiene). The relative always helps the patient, except for at the ICU where wor-

kers without nursing education and hired by the hospital, help the patients with their personal hygiene. The relatives create situations that protect the patient from being exposed. They cover the patient with blankets when washing or helping with personal hygiene and use curtains if there are curtains available.

### ***Nonmaleficence and protection***

Nonmaleficence is a principle deeply embedded in the cultural values sprung from the Confucian and Daoist philosophies which underpin the cultural values of China. It lies in human nature to care for each other and to care for the family. This is done in different ways depending on life situation and culture.

The following patterns were seen describing the values of nonmaleficence and protection in a Chinese context.

1. Protecting the patient from bad news and suffering is a generic care practice.
2. Carrying the patient's worries protects the patient and is a generic care practice.

The different patterns are described below and they are illustrated by with quotations from the patients, relatives and nurses.

#### **Protecting the patient from bad news and suffering is a generic care practice.**

An unwritten rule is that the doctor and the nurses should not discuss matters concerning the disease with the patient, before consultation with the relatives. All patients I have discussed with agree with the details about a disease are to be told to the relatives first. The relatives, together with the doctor, decide when the details should be told to the patient. Although the bad news is kept from the patient, there are several ways of indirectly showing the patient that everything has not been said, like by showing more concern to the patient, moving the patient to another ward, or by starting a new treatment.

The patients are all aware that detailed information about a disease is not directly given to the patient. "White lies" are accepted, since they keep the sick person in a good mood. This forms a paradox, a drama with different roles, the consciously unaware patient, the protecting relative and the doctor leaving the decisions to the relative. The counterparts feel safe in their roles since they know the rules of the drama. A patient, quoted below, agrees with the strategy

of not disclosing the facts about a severe disease to the patient before telling the relatives. The generic care practices which aim at protecting the patient from bad news are written in bold letters.

*The doctor shouldn't mention to the patient about a severe disease, **the doctors should tell the relatives about it. Otherwise the patient cannot stand these news...The doctor tells the relatives and then they decide, the doctor tells the patient little by hand, step by step... otherwise the patient will be scared to death very soon.** (Patient.)*

The meaning of the drama is to protect the patient from bad news, which could cause premature death, by scaring the patient to death and taking away the hope for recovery. The patient should be protected from fear of dying and should not be caused harm. According to the informants, it is not good to talk much about a severe disease, it is better to focus on the good things in life. The fear of the unknown is common to all human beings and death is one of the big mysteries of mankind. The experience of a severe disease and facing death is individual, but common features can be seen within a culture. Among informants participating in this study, it is a family matter and it is not expected that nurses or doctors act as support for the patient in difficult life situations; it is the family that has the responsibility to support the patient. The choice not to inform the patient about a severe disease is intended to protect the patient from thoughts about death and about leaving life behind, but it can also be interpreted as a protection for nurses and relatives from facing suffering and death. Death is not a natural thing to talk about and it scares the relatives. The dead body is frightening and to die in a hospital is even more frightening than to die at home. Commonly the Hu Gong washes the dead body and prepares it before funeral when the patient has died at the hospital. Below is a quotation from a nurse working at a medical ward where the patients are mainly old. She describes the fear that the relatives feel for the dead body and admits that the nurses do not find it comfortable either. The nurses do not support the relatives in their taking farewell of the dead relative, it is a family matter.

*After the patient has died we have to clean the patient, and we have to do it a long time after death...because the relatives have to take farewell **but they don't want to go inside because they are also afraid of death, scared for the patient.** (Nurse.)*

Patient want to die at home, and both doctors and nurses that I have discussed with think it is the best if a patient can die at home, since it gives a sense of normality to death. When the patient dies in hospital it is a care procedure to give



time for the relatives to say farewell and they can also talk to the nurse or the doctor if they want to. Below is a quotation showing the longing for normality in death. The culture care descriptors are written in bold letters.

*The **patients usually don't want to die at a hospital.** Sometimes the patients are sent home to die and they die in the ambulance on their way home **but it is better to die in the ambulance on their way home than at a hospital.** The relatives also want the patient to die at home, but most of the relatives want the patient to stay alive. (Nurse.)*

Discussions about death are connected to religious beliefs, and how to prepare for passing away. To talk about death is not easy and it exists as an unmentionable truth, which is a common feature in most cultures. When discussing death with patients and nurses, they usually mention and compare different religious beliefs and their influence on how death is viewed. The only Christian informant belongs to the small minority of Christians and he said that his belief in Jesus helped him to go through a difficult treatment and that he was not afraid of dying. This informant told me about the brothers and sisters (in the Christian society) praying for him and this made him feel relieved. He told me about the miracle he felt when the burden of fear was lifted from his shoulders. He felt sorry for leaving his wife behind, and worried how she would manage without him. The wife is also a Christian and during our conversation she consoled the man and said that the society will help her, she just wanted him to feel safe and happy.

Another patient had been given 10-20 more years to live by the doctor and he was now 70 years old. He said he was finished with life and did not want to live for 20 more years, he also felt sorry for his wife who would be left behind. The fear of death for both of the above quoted informants seemed to be a fear of leaving something behind and not of the unknown waiting round the corner. There are divergent views of death; to be scared, and be protected from the thought of it, and to reconcile with death and see it as a natural part of life. Bad news and death are connected to suffering, for the patients, relatives and nurses and the relatives want to protect the patient from the facts of a life-threatening disease. This can take away the opportunity for patients to reconcile with death.

**Carrying the patient's worries protects the patient and is a generic care practice.**

A patient can experience not being told the truth as a kind of betrayal by the doctor. To know about the disease is a prerequisite for being able to co-oper-

ate, and co-operation is an important prerequisite for healing according to the informants. Nonetheless all of the patients participating in the study agree that it is best that a severe disease is discussed firstly with the relatives, who in addition also want to know at an early stage. Below is a quotation of a patient describing the way information about a disease should be given to the patient. The culture care descriptors are written in bold letters.

***It is better to tell the relative first but based on my experience the doctor should have told me that the disease was severe at once and not say that it is not anything serious. The doctor said "It will only take you about 10 days to recover". When my condition was getting better the doctor told me that it will take about three months to recover. And that is important, to maintain the truth.*** (Patient.)

The patient above wants to influence the care, but is not able to do so when he is not aware of all the details about the disease. The doctors did not want to tell the patient everything at once, but told the truth step by step. The patient understands as time goes by, that he will not recover within 10 days and the doctor then gives him the next piece of truth - the recovery will last for three months. The patient quoted above changed hospital after he got to know that it would take a long time for him to recover, he lost faith in the doctor, and went to a hospital where they specialized in rehabilitation, with doctors who have a good reputation. He felt ashamed of not having recovered, of being weak and in need of help, and did not want the family to know about his condition (he is recovering from a stroke). This was possible since he came from Taiwan and only his son was working in Fujian province. The rest of the family, except for the above mentioned son, was back in their hometown and he did not tell them about his disease. His son felt that it was a burden to be the only one knowing about his father's disease, but followed his father's advice. When I met the patient, three months had passed and the patient had still not recovered. The therapy will continue for a long time since the patient had a stroke, but he can see that he is making progress which gives him hope for recovery.

Not having the whole picture causes problems when the patient and the doctor have to co-operate, and the fact that the patient is unaware of the duration of the hospital stay causes problems. Co-operation requires shared knowledge and a shared goal. The patient who is prepared for the truth, like in the below quoted statement, wants to know the truth, but cannot get it since the doctor is not prepared to give it. Below is a quotation from a discussion with a patient and the cultural care descriptors are written in bold letters.

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*The doctor was afraid of my diagnosis and didn't want to talk about the fact that I have cancer. I knew it from before through intuition, and I told the doctor to speak out, because I want to co-operate. (Patient.)*

The above quoted patient defines the doctor's inability to deal with the truth. The inability is culturally bound, since the relatives decide when to give all facts to the patient. The patient was ready for the truth but the doctor was not. The patients have one role in this drama of truth-telling and the relatives have another. The patient's role is to be taken care of, to be set aside, and this is done with love, but is not always what the patient wants.

The patient also has to co-operate with the doctors to maintain or achieve health. The relative's role is to protect the patient from the harm the knowledge about a severe disease could cause and to carry the patients suffering until the patient is prepared to share the suffering. The relatives make decisions for the sick patient which will influence the patient's life, decisions that are beyond the patient's reach. The role of the doctors and nurses in the play is to support the relatives and through them prepare the patient for co-operation when the disease is severe.

### ***Security –being assured good care***

To have a disease and to be hospitalized is a frightening and unfamiliar experience for most of us. To have a disease and be diagnosed raises questions regarding possibilities for recovery, and of course existential questions regarding life and death, depending on the severity of the disease. The quality of care and treatment is of course crucial. When hospitalized, and being in unfamiliar surroundings, a relative can make a vital difference, in giving the patient a feeling of security in an insecure situation.

The family ties among people from the rural areas are visible, a fact also pointed out by nurses. The rural areas in Fujian province have a traditional lifestyle where the whole family is involved in all matters while the urban area shows the influences of the one-child-policy and a tendency towards a Western lifestyle is evident. One could imagine that Hu Gongs were more used by the urban people than by the rural people, but in my experience it seems that equally many urban people have hired Hu Gongs. A Hu Gong is seldom hired if the patient can manage alone, and especially not if the patient is young. I have met several young patients and they have no Hu Gong for company. However, patients from the older generation often have one if they

have no relative who can be at their bedside, even if they seem capable of managing alone.

Both men and women usually work outside the home today in the urban areas. This makes it difficult to support the extended family by spending time in hospital with a sick relative. This is however not a general truth. The young nurses participating in this study commonly live with their husbands' parents, and also take turns in staying at the bedside when someone in the family is hospitalized. If they do not live together they live close to each other and have a close relationship. So although living in a big city, the family ties are tight and the family is a very important institution in the society.

The following patterns were seen describing the value of security:

1. Keeping the patient company increases the patient's sense of security and follow established traditions of generic care practices.
2. Being present, acting as the patient's voice and guaranteeing the quality of the patient's care are generic care practises.
3. Assuring the patient good care is a generic care practice.

The different patterns are described below and illustrated by quotations from patients, relatives and nurses.

**Keeping the patient company increases the patient's sense of security and follow established traditions of generic care practices.**

A feeling of insecurity emerges when left alone, according to the informants. To be together is an important part of the Chinese social life, not only in hospital but also elsewhere. This is seen in the structure of living, when young families live together with elderly family members, sharing their life and helping each other. It is a cultural care practice to care for the extended family and it gives a structure to life. An older person is not seen as a problem, rather the opposite, an old person is seen as a wise person, a person to be cared for. It is the obligation of the young family members to care for the elderly and an obligation for the elderly to help the younger generation.

Several of the young informants of this study, describe their life with the elder generation, and find it comfortable for their life situation; they have help with raising and looking after the children and the younger family can in their turn help the elderly when needed. The family ties are tight, and a young wife usually lives together with her husband's parents. The strong connection between

family members can consequently be seen in how the elderly members of the family are respected and cared for. In the urban areas the development towards the nuclear family can be seen. Nowadays the PRC has “one child families” but when looking back on history a predominant cultural value was to have many children. Today the preference is one strong child. This changes the traditional Chinese family structure and the family’s social life.

The old traditions are important to uphold. One generic care practice is to transfer the old beliefs to the younger generation and through this create stability. An example of old traditions still present in contemporary China is the generic care practices when a child is born. Many of the young informants told me about the delivery of a baby, and I also had the possibility to stay at a maternity ward and follow the care for the mother and child. The mother-in-law was usually at the hospital with the mother caring for her, and the mother in law is the most important caregiver during the postpartum period. The old tradition says that a mother, who recently has given birth, should rest for 30 days after the delivery avoid reading and nowadays also avoid sitting in front of a screen (computer) and not take showers. She also has to eat specially prepared food, and if the family can afford it a special maid is hired for the postpartum period. The food is prepared by the family and friends. One of the informants in the study, well educated in health care and with experience from abroad, told me that she did take a shower, but only when she knew that she was alone and she felt bad about breaking the tradition. She was also a little bit afraid that it would cause herself or her baby trouble. Childbirth is traditionally considered to be largely similar to illness, an imbalance between the forces Yin and Yang. Women are therefore encouraged to rest in bed throughout the period after the delivery while re-gaining health and strength. This tradition is just one among several others and it sheds light on the daily life of Chinese women.

The patient at the hospital wants and expects a relative to be by their side during hospitalisation and the relative wants and feels obligated to stay by the patient’s side. There are of course reasons why this practice (for a relative to be at the bedside instead of relying on the nurse and doctor) is present among patients and relatives at hospitals. The patient feels good when a relative is nearby. The following quotation is typical for the informants when asking about why they want a relative at their bedside. The culture care descriptors are written with bold letters.

***I want the relatives around and I feel better when they are around.***  
*The relatives are more as company, to not feel lonely and to take care of each other. (Patient.)*

To feel good is described as a feeling of security, to feel that somebody who cares is nearby and keeps one company. It is a connection to the family and to life outside the hospital. The patient is not left alone, or abandoned. If a patient for some reason does not have a relative or a Hu Gong present, the patients can keep each other company and support each other. The big patient rooms can fill the void of loneliness and of giving support to each other. The following quotation from a patient describes how the patients can support each other and that therefore relatives are not always needed.

*The patients can support each other. If there is some patient that has no relative around he can be placed in a big room so he doesn't have to be lonely. (Patient.)*

It is not only the patient that needs the company, the relatives also feel secure staying at the hospital, knowing that the patient is cared for. To keep a sick family member company is also to keep the family connected to the patient. The following quotation is from a patient and his wife. The patient is diagnosed with cancer. The culture care descriptors aiming at giving security are written in bold letters.

***I feel more security and safety when a relative is with me.***  
*(Patient.)*

*I can be at the hospital with my husband and then **we both feel more secure**. I want to be with him. (Relative, the wife of the above quoted informant.)*

The feeling of security is clearly linked to the presence of relatives – not being lonely. Loneliness is suffering, worth a sign of its own in mandarin. During my stay at the hospitals and in discussions with informants I have learned that togetherness is highly appreciated and it is not really understood why a person would choose to be on his/her own without company. To leave somebody alone is to hurt that person.

**Being present, acting as the patient's voice and guaranteeing the quality of the patient's care are generic care practices.**

It is important for the patient to have company but it is equally important to have somebody monitoring the medication, taking decisions about care and treatment and acting as the advocate of the patient when it is needed. The following quotation is from an observation at a surgical intensive care unit, and it describes both the relatives' obligation and will to stay as well as the necessity of having a relative close by. The relative is there all the time helping and

assisting the patient. The patient does not have to ask for help, his/her caring needs are interpreted by the relatives immediately. In the quotation below the relatives care practices are in bold letters.

*Morning time*

*Two relatives are sitting beside the bed; they are not talking to the patient. One relative seems to be her husband, and the other perhaps her son. The patient is suffering from pancreatitis and has undergone surgery. The patient has been at the hospital for a long time and this is her third time with pancreatitis. She is getting painkiller intravenously. **The man is assisting with steam inhalation and is also assisting his wife when she is urinating, covering the patient with blankets. He is measuring her temperature. He is constantly showing concern about his wife's condition** and I can see on his facial expression that he is really concerned (I can see it in the way he looks at his wife, the way he bends forward to look at her ready to be there for her, the way he touches her).*

*Evening time*

*The daughter-in-law is here to take care of the patient. She is bending forward talking to the patient and **helping the patient to get a good position**. The nurse is talking to the daughter-in-law showing her how to do some nursing procedures. The daughter-in-law is **washing the patient in bed, washing the arms and the legs and gives massage**. **The patient fall asleep and the daughter-in-law is standing beside the patient. When the patient wakes up the daughter-in-law gives the patient massage at the arms and legs. The daughter-in-law again washes her mother-in-law and it is only 20 minutes since last time**. The mother-in-law has fever and the nurses had taught the daughter-in-law that it is good to wash the patient often when the patient has fever. The washing in bed takes place openly, but no genital organs or breast are washed. The nurse explains that the nurses and relatives avoid washing genital organs and breast because of shyness in exposing themselves to others.*

*A doctor appears, and he is listening to stomach sounds. I can see that he is prescribing some medication, and he is documenting his ordination in the patient's journal. After a while a person, seems to be somebody from the pharmacy, appears with medication that has to be administered orally. The woman has an NG tube and is not allowed to swallow anything and this medication is a glass of some*

dark fluid. The patient has to drink this because it is Traditional Chinese medication. The doctor is a Traditional Chinese Medicine doctor and the patient has asked for the doctor although she is at a hospital more linked to the university focused on Western medicine. **The daughter-in-law helps the patient with drinking.**

*The daughter-in-law again **assists when the mother-in-law is urinating.** The woman is covered with blankets but again everything is open. The patient is getting an intramuscular injection. The daughter-in-law is all the time concerned about her mother-in-law. I can see by the way she talks to her mother in law and in her actions and her facial expression that she is concerned; she is not only doing this out of some sense of duty. (Observation.)*

When a relative is present all the time it is secure to be at the hospital, the patient can focus on healing and does not have to engage in seeking help when needed, somebody who cares for him or her overtakes the worries. The patients mention the shortage of nurses and that the patient cannot expect the nurses to always be there to fulfill their caring needs. The patient therefore needs a relative to care for him or her and to guarantee that nothing unexpected happens, and if it happens to alarm the nurse. Another informant told me about her experience in hospital without any relative nearby. She felt totally abandoned when she had no relatives around, she could not sleep since nobody monitored her IV drip, did not get food because nobody brought it to her and she had no help with personal hygiene and just taking a trip to the toilet was an adventure. Patients and relatives also mention that the nurses are in a hurry and that they cannot rely on the nurses' and doctors' attention. It does not feel good to disturb the nurses. This makes the relatives feel obliged to guarantee good care, to not leave the patient alone without anybody caring for him and fulfilling his caring needs. This shows a non-caring attitude among nurses. The statements which give information about the nurses' attitude are in bold letters.

*The **nurses and doctors are in a hurry and I don't want to disturb them if not necessary.** I sometimes throw up after the therapy and **then the nurse can see that I am feeling ill and give me something, but often they are in such a hurry that it doesn't feel good to disturb them.** (Patient.)*

The working situation at the hospital is based on patients independently caring for their own basic needs, but also on the patients monitoring and following the progress of treatment such as monitoring IV infusions. The nurses are few



and many patients have ongoing IV infusions. The patients on a traditional ward are supposed to independently care for personal hygiene with the help of relatives and assistance from nurses and doctors when the situation is not manageable for the patient and the relative (like at intensive care units). The nurses admit that this is the case, although it is not a situation they feel is satisfactory. Below is a quotation from a discussion with a nurse, the cultural care descriptors are written in bold letters.

*If there are many, many operations and the staff is working very hard, **they give the job to the relatives. Generally the relatives cannot do this job.** (Nurse.)*

The relatives also feel that the nurses do not treat the patient with dignity and that they have to be there to guarantee a dignified care. The relatives protect the patient from not being hurt by bad attitudes and non-dignified treatment by nurses.

***You cannot leave the patient alone; the nurse's attitude towards the patient is awful.** If the patient wants to have water or want to go to the toilet and need help and you ring the bell the **nurses are getting irritated. They don't like to be disturbed. The relative is a protector for the patient.** The nurse's attitude need to be changed by education, they don't like to help the patient, the nurses are only doing the technological part of the care, not the basic part of it. **It is the relative who love the patient who can take care of the patient the best way.** But it is difficult to change a system even if the nurses know how they want to change it is difficult since there are always older nurses who dictates the rules and all changes have to be sanctioned by the government, everything happens so slowly. (Relative.)*

The above quoted relative can see that the nurse's attitudes need to be changed and that this can be done with education. However, changes are slowly being made. The nurses seem to have a curing, nursing paradigm while the relative is the caring party.

### **Assuring the patient good care is a generic care practice.**

The relatives express a wish to give more responsibility to the nurses and they want the nurses to make the patient feel secure at the ward. They also want the nurse to make the patient happy, to give hope to the patient. To enlarge the nurse's responsibility by including meeting the patient's basic needs such as nutrition, hygiene, monitoring medication, mental support in the nurse's work

can be interpreted as a sign of a change in the balance between the relatives and the nurses. The debate has emerged because of relatives' limited possibilities to spend time at the bedside with the patient. Initiating this kind of change would change the nurses' attitudes toward nursing care.

There are naturally other experiences concerning nurses' attitudes towards the patient and their experience of support. It cannot be seen as a general truth that all nurses' attitudes are deficient. Some patients and relatives talk about nurses and doctors who show patience, have a good attitude and deliver good care. The following quotation is taken from a woman who has been hospitalised for a long time. She has had a Hu Gong hired all the time, but she also highly appreciates the nurses and doctors at the ward. The cultural care descriptors are written in bold letters.

*At the first time I stayed here **I felt very well I felt like being at home** and if I had medical problems I always told the nurses and **the nurses coped with my problems very well**...The therapy takes a long time. If the patient lives here for a long time and the nurses and the doctors are not good with her she will feel very bad. But now **the doctors and the nurses are very patient and I feel well.** (Patient.)*

One way of giving a feeling of security to the patient is to inform him/her about what is to be expected. The fear of the unknown is obvious in a hospital. The patient is there because of illness and the future might be uncertain. There are care practices that ease the situation and one care practice is to introduce the patient (and the relatives) to the ward and the routines. When introducing the patient, the ward becomes less unfamiliar and the patient knows what to expect. The quotation below shows the patient's expectations of how the introduction should be done. The culture care practices are written in bold letters.

*The **nurse has to make the patient secure and happy**, and all patient's are anxious when they come. **The staff nurse sees the patient and informs the patient about the ward and the routines.** **The patient should feel like being at home.** **The nurse's task is to make the patient calm and relaxed**, but the nurse has very limited time to communicate with the patient because of too many tasks. (Patient)*

The quotation above shows the patient's wish to normalise the situation, the patient wants the hospital to be like a home. The care practices mentioned include calming down the patient and helping him/her to relax in the situation.

To what extent the patients rely on doctors and nurses naturally depends on the individual experience but also on the level of care. The level of care is dependent on money and on the service that the patient buys. A patient can buy expensive care where a nurse monitors the treatment and also cares for the patient. If the patient can buy good care a caring relative is not necessary, but if the patient does not have the financial possibilities to acquire more luxurious care, then a relative is needed to take care of the patient. The following quotation is from a patient who stays at the hospital in a luxurious room, with nurses often coming in to his room and monitoring his IV infusion. The patient has a good economy and can afford to pay for his care.

*It is **not necessary with a relative around**. I have got the perfect care from the nurses. The nurses check the patient's IV infusion and change bottles when needed. Wisdom is the power of people. **If someone is sitting beside you all the time it is like waste of time**. It is not necessary with a lot of relatives around, especially patients from the countryside want to have relatives around. **You should trust the hospital care because the nurses can take care of the patients. The nurses are professionals, and there is a tradition that the only one that can take care of the patients is the relative**. The fact that nurses can take care of the patient is forgotten. (Patient.)*

The patient raises several interesting topics; in his opinion, the tradition of having a relative at the bedside is like a waste of time, and the patient should be capable of managing the stay in hospital with the help of nurses. He also points out that nurses have the ability to care for patients but that this is forgotten. This quotation is different from the other informants' statements, and gives a picture of ideal care. The nurses have the ability to fulfill the patient's need for care when they are given assets to do this, assets in the shape of time. A condition for time is to be able to invoice enough for to cover both the technical care and the care including support for the patient.

If the relatives, who have a patient at a general ward with average cost for the hospitalisation, for some reason cannot stay with the patient then a Hu Gong is hired and he/she acts instead of the relative as mentioned earlier. Below is a quotation from a patient describing how a Hu Gong guarantees good care. The cultural care descriptors are written in bold letters.

*The **Hu Gong** is a very important part in the care and the hospital should train Hu Gongs. The **Hu Gong** does a lot of things concerning the therapy they bring the patient to the therapy room and they help*

*the patient in the situation. The Hu Gong is always there. They observe the patient and the therapy and alarm the doctor if something happens and when the time is reached for IV-drip. **The therapy session is not only the doctor's it is the doctor's and the Hu Gong's. They organize this very well and the doctor and the Hu Gong are united.** (Patient. )*

The relatives guarantee that the patients are being well taken care of; they protect the patient from getting harmed, from not getting good care, and they assure the patient security in the hospital. They act as the patient's voice and as company to avoid a feeling of being abandoned.

### ***Trust –relying on relatives, nurses and doctors influences wellbeing***

One of the most fundamental factors when suffering from illness is to trust the doctors and nurses who are responsible for treatment and care. Mistrust and disappointments can prolong a recovery and create situations where insecurity is obvious.

The patients who participate in this study often mention trust in doctors and nurses as important. The patient has to believe that the treatment helps, and has to believe the doctor when he recommends the treatment. To rely on the treatment is important since it is expensive. It is therefore important that the relationship between the patient and the doctor is built on a sound ground. Although the patients know, since it is a cultural pattern that the family takes over the responsibility for decisions regarding truth-telling and treatment the patient sees trust in the doctors' decisions and treatment as one of the fundamental factors in caring for patients. And if the patient does not trust the doctor he or she simply does not follow the doctor's recommendations. The patients and/or relatives also complain to the hospital leaders if they not are satisfied with the treatments.

The following patterns were seen regarding trust:

1. Being positive and relying on doctors and nurses is a generic care practice.
2. Building confidence and trust on knowledge of and insight into the situation is a generic care practice.

The different patterns are described below and exemplified by quotations from the patients, relatives and nurses.

**Being positive and relying on doctors and nurses is a generic care practice.**

The informants participating in this study agree on the importance of getting good treatment for recovery. The patients also link their own belief in the treatment to recovery. Positive thinking and co-operation with doctors and nurses are principles deeply rooted in the beliefs held about recovery. The patient needs to know about the disease and what is expected in the mutual work for recovery in order to be able to co-operate. The patients and the relatives commonly mention education and information as tools for creating trust and co-operation. The quotation below points out that it is a choice to be positive which can be followed by the choice to trust the treatment and the doctors' and relatives' judgement. Below is a quotation from a patient who point out the conscious choice of being positive and also how a trusting relationship to a doctor can change the direction of the treatment. The cultural care descriptors are in bold letters.

***You have to face the disease, and you have to believe that the treatment will give result. You have to trust the doctor. It is a choice, to be positive.** First I didn't want to go trough chemotherapy, I thought surgery was enough, but then the doctor encouraged and educated me to understand that I have to go trough chemotherapy and I understood that I have to go trough it. My cancer is at the middle level and the expected lifetime is between 10 – 20 years. I am old now and I don't know how chemotherapy influences on my old body, whether it will destroy other organs. (Patient.)*

It is a generic care practice to rely on the treatment, and the patients have a strong belief that you can influence your own recovery by being positive and by trusting people around you. To trust the doctors' and the relatives' decisions is to relax in a situation and create positive support that helps to cure a disease or make life easier.

**Building confidence and trust on knowledge of and insight into the situation is a generic care practice.**

The informants in the study agree that trusting the doctor is connected to communication. The patients have to have open communication with the doctor and the nurses about the treatment. This is a paradox, since the initial discussion about treatment is held with relatives and there is no open communication between the patient and the doctor. The patients do however emphasize the importance of the doctor knowing everything about the patient. Below is a quotation from a discussion with an old lady, who stays at the hospital

by herself. She has no Hu Gong but her daughter visits her daily. She suffers from tension in her neck and dizziness. She chose the hospital because of the good reputation that the doctors have. She wants an old doctor to treat her, not any of the young ones. She finds it easy to talk to the doctor and stresses the importance of telling the doctor everything. The doctor did not however need to ask many questions since he already knew everything about her after the examination. The cultural care descriptors are written in bold letters.

*It is very **easy to communicate with the doctor because it's good for the doctor to know my condition**, because when doing different kinds of examinations my history is very important. In that case the doctor can make the diagnosis very easily. (Patient.)*

Trust is built on the knowledge that the doctor is skilled and tells the truth. When discussing with a patient and asking how he can be sure that the doctor tells him the whole truth, he answers that the doctor knows best and that the patient has to rely on the doctor's treatment. By saying that the doctor knows best the patient gives a voice to the paradox - to not know the whole truth nor see the whole picture, but nevertheless trust the doctor's judgement and rely on the treatment. Below is a quotation from a discussion with a patient. The cultural care descriptors are written in bold letters.

*I climbed the hill and jumped from one stone to the other and then I fell and hurt my neck and back. It happened one week ago, last Saturday. I am now getting acupuncture, and tension of the neck. **I was not afraid when I fell down and I feel well, I will recover, because the doctor told me so.** I seldom climb the hill. I arrived to the hospital on Monday. **My doctor told me to stay in bed but I sometimes just get up and walk because time gets so long. I can walk and take care of myself and I don't think it is dangerous to walk sometimes.** (Patient.)*

The man stating the above quoted, relies on the doctor, but also makes his own decisions. He is told to stay in bed because of the ongoing therapy with tension of the neck and back, but since it is tedious he decides to get up and walk. The need for company is more important than following the doctor's orders. I asked him why he does not follow the doctor's orders. He said that time gets so long, that he just had to go out of the room. The situation may improve when his wife comes to the hospital, since he then will have company. I asked him if he thinks that the treatment will help when he is not following the doctor's orders and he answered that it will help since he trusts the doctor. The man is holding the

doctor responsible for the treatment although he is not completely following the doctor's orders. This gives an indication that the patient does not fully trust the doctor's recommendations for recovery, although the informant tells me that he has chosen this hospital because of the good reputation the doctors have here. It is difficult to understand why he does not follow the doctor's orders since he simultaneously praises the good care. It might be that the patient is not fully satisfied with the treatment since the recovery is not sufficiently fast but he does not trust me enough to tell the truth.

Traditional Chinese Medicine is chosen by some of the informants and it is chosen due to good results of treatment, when the patient suffers from a chronic disease or because of its long history. TCM is seen as powerful, good and fits the Chinese people. The informants also mention that they believe in the philosophy which forms the basis for TCM. The quotation below reflects thoughts of a patient who believes in TCM and chose this method of treatment because of its long history.

*I get acupuncture, massage and IV drip. I believe in Traditional Chinese Medicine philosophy, it comes from the elderly. The doctor knows me and knows about my medication and the nurse always informs me about the therapy. The nurse is always very patient and the doctors are very good. There are many diseases and a doctor has to know a lot. (Patient.)*

Trust is an important value in the patient's world. Trust in the doctor is gained through the relatives and their decisions and actions. The initial co-operation is the relatives' responsibility and the patient is set aside. Setting aside the patient is not done as a violation of the patient's dignity or autonomy, but is done based on the will and obligation to care for a sick family member.

### ***Harmony – the ultimate goal***

It is important to be able to feel joy and harmony - to be happy. Life is connected to death and you ought to be thankful for the life you are given, make the best of your life, and not worry. The ultimate goal is to be in harmony. Some of the informants are old and they compare life when they were young with the life of today. Generally they talk about the war against Japan and the Cultural Revolution. They find it important to value life, when they have seen so much death earlier in life. Their message is not to worry about small things in life, but to appreciate the life you are given. One informant, who took part in the civil war and the war against Japan, formulates it as follows:

*My life is important for those who die; I have to live for those who died. (Patient.)*

Life is valuable, and the woman feels like she has to live a good life because she was saved and not killed; it is an obligation to her. She has to remember those who died and live a happy life. This is a part of not causing harm to those who died by living a bad life, she always has to remember to live a good life to honour those who did not get the opportunity to live.

Harmony is embedded in the Chinese culture. It is seen in the philosophy behind Traditional Chinese Medicine. Health in Traditional Chinese Medicine is viewed as harmony between the forces of Yin and Yang within and between the body and its environment. Illness in contrast is an imbalance or disequilibrium of Yin and Yang. Qi is the source of life and the energy that is circulating in the body. In Traditional Chinese Medicine the physicians focus on interruptions and blockages of Qi which is seen as the driving force of cosmos and human life. The concepts of Yin and Yang have been a part of various forms of Chinese philosophy since at least 400 BCE, if not earlier. They play an important role in both Taoism and Neo-Confucianism, along with various popular folk belief systems.

The following patterns were seen describing the value of harmony:

1. Following the philosophy of TCM is a generic care practice.
2. Consciously influencing personal harmony, and state of mind is a generic care practice.
3. Trying to maintain and achieve hope and harmony is a generic care practice.

The different patterns are described below and exemplified with quotations from the patients, relatives and nurses.

### **Following the philosophy of TCM is a generic care practice.**

The value of harmony is seen among patients at the hospital linked to the University of Traditional Chinese Medicine, but also in the way that the patients view their life. To have harmony in mind is to have peace of mind. To be in a good mood and think positive thoughts creates harmony. The patient has to find the positive things in the situation and laugh every day. The older patients practice acupressure and acupuncture to open up the flow of qi in the body and through this create harmony in the body. This is important for wellbeing



and healing. Below is a quotation from a discussion with an old man who described “good mood” as an important cultural care practice to maintain health. Acupuncture is also an important generic care practice to achieve and maintain health.

***You have to laugh, be in a good mood** (to maintain health, authors note). I am doing acupuncture on myself, and also on others when needed and when I am asked to do it. (Patient.)*

The patient mentions Tai Chi as important for maintaining health and harmony. Tai Chi can be defined as moving the body in special positions to open up for the flow of qi in the body. Tai Chi is taught in school and is practiced by many in China. In the morning hours the parks are crowded with people practicing different kinds of Tai Chi.

Tai Chi is seen as having a positive influence on maintaining and achieving health. Diet is also an important part of the daily life in China and it is often mentioned as a way to uphold health. It is important to have special food depending on your disease. Food is seen as a support for health and a treatment for gaining health.

***It is important to get good nutrition to feel well and the relative gives the patient the food he or she want to have and the relatives believe is good for the health.** The food is especially important for the patients just undergoing surgery and who has undergone surgery. The food has to support wound healing (a special kind of fish for example). The hospital is only providing simple food, not the special food the relatives want the patient to have, so the relatives is often making the food for the patient and taking it to the hospital. (Nurse.)*

One of the informants, a patient at the Western-oriented hospital, wanted to have crabs of a special kind made in a special way to speed up his recovery. The hospital does not provide the patients with different dishes so the relatives had to take care of this matter. The above mentioned patient had crabs (who were still alive) in a bowl close to his bed and a person from the kitchen at the hospital made the crabs the way the patient wanted them to be done.

Illness and suffering show disharmony in the body. It is important not to worry too much about the disease, since excessive worry causes disharmony and can cause premature death. To avoid negative thinking is important for maintaining health. If the patient worries too much the negative thoughts will prolong his

disease and act as an obstacle for healing. The patient should instead be open for co-operation with doctors. Positive thinking is linked to healing and the quotation below shows the cultural care descriptors aiming at maintaining and achieving harmony. The cultural care descriptors are written in bold letters.

*... It is **not necessary to think too much about the disease**. In Beijing there is an anti-cancer association, so many people who have had cancer **they live for a long time because they keep their minds very happy and they don't worry too much about it**. People worry too much about diseases, **when they learned to know that they had cancer they died very soon** ... we don't need to worry too much of the disease but we should be active to get the treatment. In your mind you shouldn't worry about it. ...The relationship between neighbours is important. **It is also important that you always are in good mood, and feel happy**. Don't think about small things and let them bother you. ...You should also be talkative, otherwise your mind will not keep clear, and you also have to read more, to learn more. Try to keep aware. If you don't think much every day you will get silly, loose your cleverness ...**You should care about the big things in your country, but you shouldn't think about small things, not so important things**. **If you have a disease 30 % is to get treatment and 70% is up to you, is about luck and own will**. (Patient.)*

To be humble, not to worry, not to quarrel with neighbours and to focus on the small things in life is important in order to maintain harmony. Life will be both longer and happier if the above stated rules are followed. The above quoted statement also shows the importance of not letting a disease and a diagnosis overshadow life.

### **Consciously influencing personal harmony, and state of mind is a generic care practice.**

It's important to have harmony in your mind, to keep a good attitude, and not let the negative thoughts dominate life. "Good mood" is to feel harmony and a person has a conscious influence on his/her own thinking and acting. "Good mood" is gained through laughter and positive thinking. Many informants mention positive thinking and not letting the illness rule life. It is important to have good relationships to people around, that which will also increase harmony as described above. Good family relationships are also important for keeping a positive outlook and harmony in life. It is important that the parents have a good relationship to the children. A good relationship to the family is seen as an important care practice. One of the informants talks frequently about her

grandchildren and how important they are for her health and harmony. Below is a quotation from a discussion with this old lady.

*Meeting children and grandchildren is important and it gives you a good mind. It is important to have close relationship to family. (Patient.)*

The patient might also want to hide the suffering from the relatives and this way he or she does not get the support and help needed. The patient does not want to show suffering and cause the relatives suffering. Below is a quotation from a group discussion among nurses about hiding suffering from relatives. One reason for this can be the desire not to cause suffering and another can be that the patient cannot afford an expensive treatment and does not want the family to take a loan for his or her treatment.

*Many patients will show their feelings to the relatives but to the others, like **to the strangers, they try to control themselves** and it is also about how the patient can manage, how is the relationship with others you know some patients are highly educated maybe they want to be strong enough and then they will keep the feelings inside of himself or herself without showing to the relatives how he or she suffers because they think then the relatives will suffer so sometimes the relatives don't worry because they don't know. (Nurse in a group discussion.)*

Harmony is important and the cultural values in Eastern cultures emphasize interpersonal relations. To protect the relatives from knowing about suffering is a way to keep harmony in life.

Trying to maintain and achieve hope and harmony is a generic care practice. Harmony can be seen in this study in different ways. It can be understood as the peoples' way of maintaining "qi" and harmony and how this is shown to others. Harmony is maintained through exercises, movements and meditation which generate energy (qi) and they are deeply rooted in the culture. Qi can be described as energy and the energy can be collected through Qigong. Qigong is the foundation for Thai Chi. Qi is stored in the kidneys and in the liver, and these organs are very important in Traditional Chinese medicine. Acupuncture is focused on these organs. Acupressure is an important generic care practice to maintain qi. Below is a quotation from a patient at a Western oriented hospital. He practiced acupressure by himself and he wanted to have space for doing Thai Chi as well.

*It is also **good to do exercise** (to maintain health)...Some exercises are good for your health, like **Tai Chi**. A lot of people are aware of the importance of Tai Chi both young and old. Tai Chi is not heavy. It has slow movements and is suitable for everybody; every part of the body is getting movements. **You can increase Qi by practicing Thai Chi.** (Patient.)*

The practice of Tai Chi is not always possible at the hospital due to the patient's condition and to the limited space for the patient. Outside the hospital Tai Chi is practiced in the parks and the participants are on average middle-aged or old, but at school the children learn how to practice Tai Chi. To practice Tai Chi outdoors is congruent with the belief in finding harmony in connection with nature.

To have harmony is to have accepted the situation – to get on the road of hope. It is a process to go through all the different stages when losing hope – grieving, not wanting to live, to not finding hope and meaning with life. Life is important and the informants point out that we have to see life as a gift and use our life for the benefit of others. The family is important in supporting the patient but also the doctor with the treatment and the nurse educating the patient is also essential for gaining hope for life. Below is a quotation from a discussion with a lady at the rehabilitation ward and she tells me about her life when she got a stroke that gave her difficulties in the left arm and leg. The cultural care practices are written in bold letters.

*It was difficult to sleep because I had pain in my arm and it kept me awake. If I cannot sleep I listen to music and read newspaper. I live with family and I get support from my family. **The family tells me that I will recover and I have a strong believe that I will recover. The good progress is also giving me hope.** When I am here I can show other patients that they can recover. **I show to the other patients that I am doing well.** The first time at the hospital. I could not walk. **I had no hope for the future. I thought I cannot live but after I came here the doctor and the nurse convinced me and gave me hope, through educating me, they told me that I will recover.** I am disabled and I look at TV and listen to radio and read the newspaper about disabled people and then I started to feel hope. Family supported me, but it took a long time to accept the situation and to recover. **The family is very important.** Because I am a teacher and my children are also well educated, they often came here and talked to me and I felt very*

*bad. It took a long time to recover hope. It was a lot of crying and a lot of tears before I could feel hope. (Patient.)*

The woman spoke about the first time when the disease was overwhelming her, how sad she was, how she did not think of further life, but gradually she gained hope again. Hope was gained through education and support from the nurses, doctors and of course from the family. Hope is connected to the acceptance of the disease and it took a long time to accept it. To have a strong belief in possibilities to be cured from the actual disease is connected to positive thinking. A personal religious conviction also helps the patient to fight against the actual disease. Below is a quotation from a discussion with a male patient describing in what way his spirituality helps him through a difficult period. The cultural care descriptors are written in bold letters.

***My belief in Jesus helps.** I have been enjoying life and I am happy to have got all these days and I know my days are counted no matter what I want. I am enjoying every day. Jesus gives love. **I am not afraid of dying because of my belief in Jesus. My religion gives me strength to fight against the disease.** (Patient.)*

In PRC Christianity is a minority religion. Most of the people are Buddhists, and some of the informants are atheists or Marxists. The informant's belief in Jesus as a saviour and his courage in discussing death and facing it is not common.

To strive for harmony is a way of living. It is embedded in the culture and the individuals' religious belief is coloured by the cultural values of harmony. A person's health is in a constant state of change. Suffering is a part of life and it cannot be fled from, it has to be accepted, an opinion clearly seen among the informants.

## **Visualization of practices, values and beliefs among patients and relatives in a Chinese setting**

In this chapter the above described themes and patterns are visualized. They are briefly described, and they reflect the previous description of Chinese culture and previous research concerning suffering and caring. To understand the Chinese patient one has to understand the view of the human being in China. According to Geertz (2000a), one has to understand what is happening, as well as how and why it happens to understand a culture. To attempt to capture the spirit of the human being in a Chinese context and to understand why people

act as they do is hazardous to a foreigner and it is a question of guessing (cf. Geertz 2000a) and endeavouring to guess correctly. The Chinese patient at the hospital seems to be unobtrusive; he or she is not actively taking part in the decisions regarding treatment and caring procedures and is not left alone, but always cared for and conscious of the importance of remaining in harmony. The patient does not show caring needs regarding comfort and closeness to the nurse but expects a professional attitude from her.

What are the patients doing, how and why – what meaning does it have to be unobtrusive? The relatives have an active part in the care for the patient, why is it like this, what is the meaning behind it? These questions will be answered through a discussion of the patient, the relative and the generic care practices, the suffering human being and the values and beliefs underpinning the generic care practices. These issues discussed in the light of previous research and the previously presented social structure dimensions of China.

Below is a visualization of the practices, values and beliefs in generic care. The patient is in focus and although all patients are individuals with individual needs and expressions there are some characteristics that can be seen among many of the patients. The generic care practices are the tenets that have been outlined and the values and beliefs that undergird the generic care actions. The beliefs, seen on the right in the figure 4, below, form the basis of the values seen in the middle of the figure. The connection is visualized by an arrow pointing from beliefs to values. The arrows from values to the generic care practices show that the cultural values influence care practices. The characteristics of the patient and relatives which are related to caring practices aiming at understanding and alleviating suffering are described.

### ***The patient, the relative and the generic care practices***

Generic care is visible in a Chinese context. The family is the primary caregiver (cf. Haigler et al., 2004). Berry (1999), Bonura et al (2001) and Leuning et al (2000) have in their studies in various cultures, found that generic care is important to the families since it is a way to show respect, to protect the vulnerable family member and to keep the family united.

The patient at the hospitals where the study was conducted seems to be unobtrusive, and the family takes over the responsibility for the sick family member's wellbeing (cf. Wang & Pang, 2000). I interpret this as a sign of a mutual dependency within families; a sick family member can rely on being cared for. It is also a way of maintaining wholeness, to avoid splits within the family

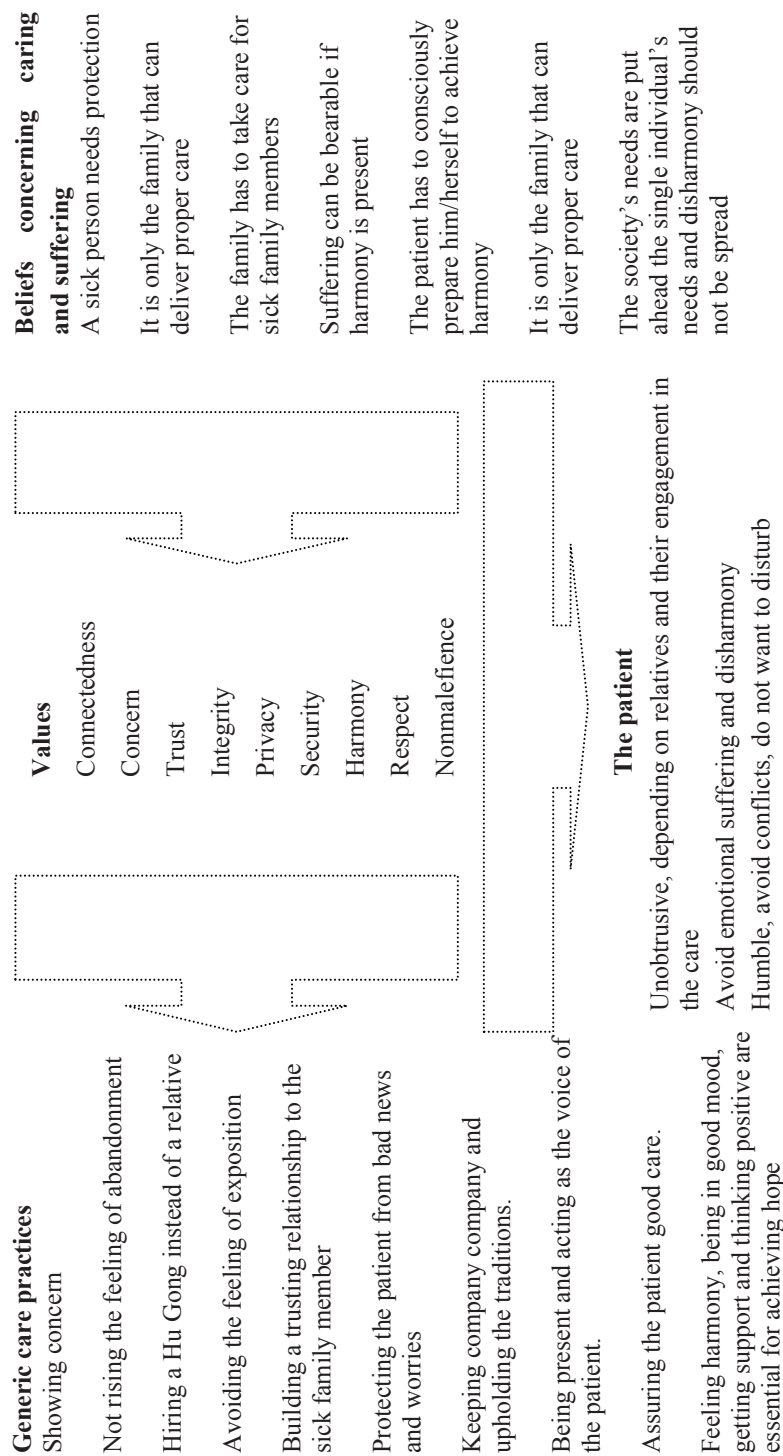


Figure 4. The visualization of the practices, values and beliefs in generic care.

caused by a member's absence, an interpretation also congruent with Wong and Pang (2000). This can be linked to the cultural value of being connected to a group of people, a family, to be a part of an entity. The family and the relative are at the hospital to protect the patient from getting worried by bad news, to support him or her and so that the patient not will feel abandoned. The family is there as a guarantee for good care. Bondas (2000) and Haigler et al (2004) point out the importance of teamwork where the family is one counterpart in the caring process, and this can clearly be seen in the Chinese context. The family who cares for the sick family member needs support and Wiles (2003) describe the confusion family caregivers experience when not able to find support in their caring role, and Winslow (2003) emphasizes the family caregivers need for support in their caring for the sick family member. In the Chinese context the support is natural since the nurses and doctors see the family as a part of the caring process.

The Chinese cultural value of being a person in a social relationship (cf. Kao et al., 2006) is clearly seen in the hospital world. The patient is not left alone and the relative is acting for the benefit of the social relationship. People are not considered to be full human beings without being connected to each other, therefore a patient who is abandoned by his/her relatives is an unusual sight. The patient does not have to use his/her own voice regarding health/illness and treatment since the family is the advocate. By being there with the patient the family upholds the social norms.

One of the social norms is to avoid exposing the patient to strangers, and caring for the patient's basic needs such as nutrition and hygiene is done by the family (or hired relative, a *Hu Gong*). The family supports the patient with positive thinking and through this also increases harmony. The family also creates privacy and integrity in a crowded room by protecting the patient from being forced to show emotions and supporting him/her to maintain control. Doing good for others and being a good person is of great importance in China, and doing good is to protect the person who is ill and weak (cf. Chen, 1996, 2001). Respect for the nurses' job is pointed out, and a person who is doing a good job is worth respect but a person who is not, has not earned the respected. The respect seems to be linked to "doing"

Commonly it is the son or the father who is responsible for the decisions regarding treatment, and also regarding payment for the hospitalization. China has a long history of strong relationships between family members and according to the informants it is the parents' responsibility to raise the children and the children's responsibility to care for the parents. Important matters are dis-



cussed in the family and the elderly generation is highly valued and respected in Chinese society (cf. Lee et al. 1995; Wong & Pang 2000). The united family is a phenomenon which is slowly disappearing, because of the “one-child-policy”. The changes can be seen more rapidly in urban areas and more slowly in small cities and rural areas. Regardless of this families still play an important role for the average Chinese person. Family and home are important for Chinese people and home is a place where they can feel safe and have a sense of belonging (cf. Kao et al., 2006; Wong & Pang, 2000). The family consequently transfers the feeling of belonging and connectedness to the hospital.

Each person’s health and harmony contributes to other people’s harmony, and doing good for others as well as being a good person is important in the Chinese culture. A human being is not isolated; everybody belongs to other people and everybody influences each other. Harmony and balance are the optimal state of being in Chinese tradition, but life is dynamic and harmony is not always present. The patient strives to maintain health and harmony although he/she is suffering. Harmony is essential for the patient; it keeps the patient in a good mood and positive thinking creates harmony. The obligation to be thankful for the life that is given is a feature that is obvious among elderly patients, but also younger patients show humility towards life. Harmony is dependent on the person’s own capacity, and the patient can consciously strive to uphold harmony regardless of suffering. Through having harmony, the patient as well as the others surrounding the patient can spread harmony. A person’s health changes constantly and suffering is a part of life and it cannot be fled from, it has to be accepted, and suffering is disharmony (cf. Chen, 1996, 2001; Kao et al., 2006; Mok, 2000; Mok & Tam 2001). By keeping suffering private, harmony is upheld, or at least an imaginary harmony is present. To share suffering is to spread disharmony. The fact that the patient understands that he or she has no absolute control over the world helps them to accept misfortunes, disabilities and limitations in their life. Conflicts are avoided because they disturb the harmony between person and environment or among people, and this can be seen in the relationship between doctors and patients where no decisions are openly questioned (cf. Chen, 2001). Relatives question treatments and complain to hospital leaders if they are not satisfied.

Co-operation is mentioned by the patients as one of the most important elements of treatment, and as a powerful tool in achieving health. To co-operate can be seen as following the doctor’s instructions. The patient is not an independent part of the co-operation, since he/she is protected from worries about his/her situation by relatives. A discussion about different treatment methods is therefore not held. The co-operation is done with the help of the relatives,

and their experience of the doctor's treatment. If the patient is not satisfied with the treatment, he or she simply chooses not to follow the instructions, instead of complaining. Complaints are not made in public, since the person who gets the complaint loses his or her face, (although according to nurses complaints about care are given, but then mainly from the relatives). It is not congruent with the Chinese culture to openly complain. To openly ask for help seems also to be avoided and the patients avoid approaching nurses if not necessary, since they do not want to disturb and show their need for care. This can be due to the patients' experience of nurses' workload at the ward, but is more likely due to the patient's unobtrusive role at the ward and the family's protection of the patient.

### ***The suffering patient***

When talking about suffering, health is always present. Health is connected to harmony between Yin and Yang according to Traditional Chinese Medicine (Chen, 2001) and striving for harmony is embedded in the Chinese culture which forms a framework for understanding health and illness.

The characteristics of the Chinese patient have several similarities with the behavioural stage described by Morse (2001) which is named the "enduring phase" in a praxis theory about suffering. Morse describes enduring as a condition, not directly connected with suffering, but which precedes suffering. A person who suffers, can move back and forth between enduring and suffering, according to his/her own needs and according to the situation. Suffering is according to Morse (2001), a process of appropriate behavioural norms and the Chinese patient seems to endure the situation in public and suffer in private. It is not appropriate to share suffering with strangers, and sometimes not even with the family, but through sharing the sufferer get confirmation and relief (cf. Eriksson, 1994, 2006). Charmaz (1999) describes that suffering can slip into the background when other needs are on the surface. These other needs can in a Chinese context be interpreted as social needs; to fulfill the norms and expectations that people surrounding the sufferer have. One's own suffering is not shown in public because that creates more suffering for people around and disturb harmony. Harmony and hope belong together.

Harmony is a concept embedded in the Chinese culture and is seen as a part of daily life. Yin and Yang, Qi and achieving harmony through different exercises and diet is a part of daily life in hospital. The Chinese patient endures suffering and focuses on harmony and hope, a procedure also supported by the family. To find harmony although suffering can be compared with the results Morse

and Doberneck reported (1995) where they found a connection between hope and the enduring phase. The patients endure suffering in order for hope to be sustained, and patients who were aware of a life-threatening situation were constantly “hoping against hope”. This can be seen in the Chinese culture, in the enduring stage. The patient is supported to endure in order to “not lose hope”, and the truth about a severe disease is consequently not told to the patient, which leads to prolonged enduring. The strategy of not telling the truth aims at keeping hope alive.

Hope is in the Chinese context of vital importance and it cannot co-exist with fear. An important generic care practice in the Chinese context is to uphold hope and protect the patient from fear and suffering. Fear can occur when the patient faces a severe disease or death. The patient is encouraged to get on the road of hope, by being kept unaware of a severe disease. Suffering from physical pain or from mental disorders is seen as less severe than suffering due to fear or social circumstances. Pain can be treated with medication but other suffering is difficult to treat, and the patient can be afraid of losing hope. The relatives protect the patient from suffering, and in contrast to the Western description of suffering, the patient in China is protected from living through the drama of suffering (cf. Berry, 1999; Bonura et al., 2001; Eriksson, 2006; Wiklund, 2000). The suffering is not confirmed by the relatives or the nurse, the patient is encouraged to endure the suffering. The patient is not encouraged to face the suffering - he/she is protected from facing it. The patient is not encouraged to ascribe a meaning to the suffering and to let life take a new direction through the suffering. In China the relatives participate in the drama of suffering and carry it until the patient is ready to face it. The patient is encouraged to feel harmony although the situation is insecure. The patient can influence himself to achieve harmony.

### ***Values underpinning generic care practices***

In the following text values are written in italics. Some of the values in nursing seen all over the world such as the values of *respect* and *concern* for each other and not causing harm to other people (Leininger, 1998). This can be seen in peoples' will to care for each other and is described in both religious literature as well as in scientific and popular literature. Eriksson's theory of caritative caring (1991, 1993, 1994) describes love for the other as the foundation of caring. Leininger (1998) describes filial love (family and love to others) and both Leininger and Eriksson see the mother's love and care for a child as the fundamental motive for human caring. Ray (1994) agrees and says that nursing was built on the foundation of love expressed in mother-

hood and in the religions. Respect and concern are seen in the social structure dimensions in China, and they are important values in the collected material. Even though they do not form a theme of their own, they are part of the other themes. Concern and respect are like red lines running through the whole process of hospitalization. Respect is shown to family members and especially to the elderly in the family. But although respect is seen as a value undergirding generic care for the sick family member, respect is also absent. Respect for the other is not seen in the social system in China. All people do not have access to health care; people who have economical resources get good care while those who are poor are not cared for. This situation is not unique to China.

*Nonmaleficence* is a value which is not unexpected in a study like this. It is embedded in the cultural values sprung from the Confucian and Taoist philosophies which undergird cultural values seen in China. The will to not cause harm is in this study represented by “white lies”; not telling the truth and acting in a drama with given roles in the generic care for the patient. Xu (2004) in her reply to Hanssen (2004) discusses the Chinese way of acting in a situation where a patient has a life-threatening disease. “White lie” scenarios are according to Xu not uncommon to Chinese physicians when it comes to a life-threatening diagnosis such as terminal stage cancer. This fact is also visible in this study. The physicians want to shield the patient from the potentially negative effects of overwhelmingly bad news, since telling the truth may from a Chinese perspective hasten a negative health condition. The informants in this study agree that truth telling might cause harm to the patient, but the patients also appreciate truth telling because it can ease co-operation with doctors. This can also be seen in Pang (1998a, 1998b) who discusses the nurse’s view of disclosure of information to patients and the moral issue it raises. Tuckett (2005) says that truth telling is important for patients since it promotes trust and comfort in the relationship and patients want honest and clear information. This is also seen among patients in this study; they want to know the truth about their disease, but they also agree that the relatives have the responsibility to decide when the truth should be told.

Chinese family ties are described in literature (cf. Jakobsson, 2001; Xu, 2004) and although literature does not explicitly describe relatives’ role in hospital when a sick family member is hospitalised, it does describe the tight family ties and the role of the family in Chinese society. *Connectedness* is an important value in Chinese generic care. A person does not exist alone in the Chinese culture, he/she is always connected by social relations. Kao et al (2006) link the view of the human being in the Chinese culture to the philosophies underpinning the values which dominate the worldview. Confucianism emphasizes

the significance of a social being by explaining that a person cannot exist alone but can only learn and develop in interpersonal connection within a social network. The patient is in a vulnerable situation and as described above the relatives protect the patient and act as the patient's advocate. The relatives do not abandon a sick family member, they care for him or her. Death scares, mainly the fear of leaving something behind is scaring, not the fear of the unknown, according to the patients and relatives.

The patient can *trust* the family. The family is the social network through which the individual exists. The patient's vulnerability is discussed by Sumner (2001) who points out that it can be determined through communicative acts and by sharing suffering with a compassionate person. In the Western culture compassion is one of the highest valued characteristics of a nurse, but in the Chinese context the compassionate carer is the family. Sharing the suffering with a compassionate person allows the sufferer to work through and interpret the suffering according to Sumner (2001), but in a Chinese context the sufferer is not supposed to work through suffering, rather the opposite, the sufferer is protected from suffering.

To be able to keep *integrity and privacy* is an important value, and also seen as treating the patient with dignity. It is difficult to create space for integrity and privacy at a Chinese hospital. The patient and the relative create a private space in the crowded room. It is accepted that the physical space is limited, but it is not common to expose feelings. The integrity is an inner integrity where feelings are not shown and privacy is created when the family moves the "home-like" situation to the hospital where the patient can feel safe and *secure*.

Harmony is a concept rooted in the Chinese culture as described above. Among the informants harmony is a state to strive towards. Harmony and health belong together and there is no health if there is no harmony. Yin and Yang are the forces that make up harmony and diet, medication and movements can influence harmony in body and mind. Illness is an imbalance or disequilibrium of Yin and Yang. Qi is the source of life and is the energy that is circulating in the body. The informants' view of health, illness and human being is colored by the understanding of harmony. At the hospital the patient strives to achieve harmony and this is done in different ways, by supporting the body system (diet) by mental support (for example Tai Chi) and by the responsibility all (patients and relatives) have to not cause disharmony to others.

### ***Beliefs directing generic care***

The statements titled beliefs consist of the knowledge that is derived from the themes and patterns found through analysis. The beliefs are seen in the patients' and relatives' expressions of their life at the hospital concerning their actions and the practices seen at the hospital. They are founded on the values surrounding life for the above mentioned group at the hospital. The beliefs are written in italics. The beliefs represent the "thick description" answering questions about the meaning of certain actions. Each "belief" is formed by comparisons within cases, listening to the voices of several informants and observing several events.

The first belief or statement is "*A sick person needs protection*". The patients have through verbal and nonverbal (observed) communication shown that they want the relatives to be at the hospital, to be their advocate and to protect them from being harmed and to guarantee good care. This is a recurring pattern in the themes presented above. I can see the protection of the patient as one of the most vital practices the family is carrying out when caring for a sick relative at hospital. The following belief is derived from this practice; "*It is only the family that delivers proper care*". The belief is that the family is the institution which can deliver care, the doctors and nurses are professionals and their task is to act professionally, which does not include generic care. "*The family has to take responsibility for sick family members*" is the third outlined belief and this is due to the strong family ties and the Chinese view of human beings as connected to each other. People rely on the family and the family institution is powerful in Chinese society.

Health is discussed among the patients and relatives at the hospital whenever talking about suffering. The main goal with treatment is to be healed, to achieve health. Health is seen as harmony and illness as disharmony. "*Suffering can be bearable if harmony is present*" is a belief evident at hospitals. The relatives and the patients strive to find ways of achieving harmony; "*The patient has to consciously prepare him/herself to achieve harmony*". Harmony can be reached through different methods, by having a correct diet, by practicing Tai Chi, by not having to worry and by thinking positive thoughts that give a positive outlook of life. To have harmony and accept life as it is, is a goal. The patient has to rely on the relatives' and doctors' judgement and co-operate. The relatives keep the patient from suffering by being supportive and helping the patient to maintain harmony. An important part of maintaining harmony is to let the patient maintain the hope of recovery and protecting them from worry. "*Society's needs are put ahead of the single individual's needs and disharmony*

*should not be spread*". The patients, relatives, nurses, doctors and Hu Gongs know their roles. The doctor does not inform the patient about details concerning a disease, prognosis or treatment without consulting relatives and neither does the nurse. The relative does not let the patient know facts about a disease that might hurt or harm him before he or she is prepared for the news. The patient is not abandoned and the relatives try to guarantee good care as well as privacy and integrity, although the hospital is crowded with people. Society needs harmony to function and illness is disharmony. The single individual has to uphold the harmony of the society.

## **The nurse's voice – practices, values, beliefs and meanings concerning suffering and caring in a Chinese setting**

The second biggest group of people seen at hospitals are the nurses. They were seen hurrying between different wards with different tasks in their light coloured dresses. They all wore a small cap on their head, regardless of their professional standing. What were they doing, what care practices could be seen and why are they acting as they do? These questions had to be answered, when forming



*Photograph 10. Nurses at a ward.  
(Nyback, 19.05.02)*

“thick descriptions” of cultural phenomenon according to Geertz (2000a). One must firstly describe the place where the nurses acted.

In hospitals the nurses co-operate with doctors and in order to understand the nurse's care practices, parts of the doctor's work also have to be described. Above a photo of nurses working at hospital can be seen. The photo was taken during my stay at the ward, and the nurses' way of dressing and their environment can be seen. The board in the background show the routines at the ward. The nurses at the picture are not acting as informants in the study.

Nursing seems to be a female profession in Fujian province. I have not met any male nurses at the hospitals I have visited nor have I met any male nursing student. Nursing education in the PRC is attracting an increasing amount of applicants and, based on the informants of this study, an increasing amount of students show a deep interest in nursing. Nevertheless, several of the students applying for nursing are doing it out of certainty of getting a job after their education.

Creating models of nursing based on the cultural values and the worldview of the nurses' environment might increase the appreciation of nursing and attract even more students and researchers into the area. I asked one of the head nurses if nursing as a profession is highly valued and she said: "things are getting better". The Chinese nursing society is working hard to raise the status of nursing. I then asked her if she could see nursing as a good career for her (presumptive) daughter, and she answered that she would not. She would prefer her daughter not to work as a nurse since it does not have an equally high status or salary as other academic careers. This argument is well-known in Western cultures as well, nursing is not highly valued today, and other professions with higher status attract both parents and younger people. Nursing is not necessarily even valued as a valuable profession among relatives and patients. It is compared to being a maid or a servant and it is viewed as a technical job, not consisting of much emotional support for patients or for relatives. Even though the nurses themselves view their work differently, they do not either consistently value the job highly.

Nurses are educated either on a diploma level or Bachelor's level and some at Master's level. Most of the nurses working at the hospital have got their education from the university linked to the hospital. Their working days are split, usually they have the morning shift, some hours off for rest, and then continue with an afternoon shift. The nurses can rest at dormitories or at rest rooms in the hospital. All hospitals do not provide possibilities for nurses to rest at the wards during the free hours. There are also evening nurses and night nurses. Every morning there is a ward meeting, at the wards I have visited, with both nurses and doctors working at the ward. The care plan for every patient is general and the specific part is ordered individually by the doctor.

The development of TCM and Western Medicine in the PRC is evolving simultaneously. The different sciences function side by side, and universities as well as hospitals have different departments for development and research within both areas. There are several doctors at each ward and at an average ward there are 3 nurses/20 patients during daytime, naturally depending on what kind of



ward is in question. The ratio is different at intensive care units as well as on CCU. The duties are divided depending on task and at both hospitals I could see that one nurse is responsible for IV infusions and one or two nurses (depending on the amount of patients at a ward) are responsible for carrying out doctor's orders (oral medication, injections). The doctors are either trained in TCM or in Western oriented Medicine. The nurses are trained in both Western Medicine and TCM but depending on what university they have attended the focus is on either Traditional Chinese Medicine or on Western Medicine. The universities oriented toward Western Medicine have increased the lead in higher education for nurses (Bachelor's and Master's education) but Traditional Chinese Medicine is rapidly catching up.

The PRC today is struggling to catch up with Western countries regarding technology at hospitals. The latest technology is bought, due to better economy, but also due to the fact that good equipment will help the doctor to diagnose the patient correctly, and will help the nurse to carry out her nursing care in a safe and lifesaving way. Technology is highly valued among patients and nursing staff at the hospitals. This can be noticed in the way that modern equipment in many ways supports an old fashioned nursing care. The bio-medical model has been adopted and this model includes high appreciation for technology. This can be seen in the routines at the x-ray unit in a big hospital, where all patients should be treated the day they arrive to the hospital.

Patients are commonly treated with intravenous infusions both at the wards and at the outdoor clinic. At a big hospital in the province, the newly built outdoor clinic has one room for patients with IV infusions and one room for patients getting injections and several outdoor patients were getting their IV infusions sitting in the room, side by side. The medication given intravenously differs depending on hospital. At the Western oriented hospital the medication often consists of antibiotics while the medication at the hospital following the traditional Chinese medicine is commonly based on herbs and given as supportive medication. Intravenous infusion is seen as a powerful way of getting medication. This is a fact affirmed both by nurses, doctors and patients.

The nurses protect themselves and the patients from infections at the wards by using masks when administering medication. The infection control is rigorous and every infection has to be reported. The nurses commonly discuss infection control and it is naturally difficult to keep infections out of the hospital with many relatives at the wards. This was one of the biggest problems at the paediatric ward at one of the hospitals, since they were taking care of both infectious children and children with leukaemia. The nurses found it difficult to protect

the vulnerable children from infections since it is difficult to control visitors.

In the following chapter the various themes emerging from the data concerning patients and nurses will be presented. The different themes are presented as subheadings, the patterns are in bold letters and the quotations are in their original, from the field diary or from discussions. The presentation of this chapter ends with a conceptualization of how patients' and nurses' values, practices, meanings and beliefs concerning suffering and caring are seen in relation to the different themes and patterns.

The themes presented are following: The obligation to act with professional skills and within the tradition, communication as a caring act and helplessness and hope – the different faces of suffering. The themes contain the values apparently dominating the nurses' life at hospital and answer the question of why nurses act as they do. Within the themes patterns are presented. The patterns form practices. The themes and patterns form the underlying beliefs that influence the actions and reactions in caring for the suffering human being seen from a cultural context approach.

### ***The obligation – to use professional skills and act within the tradition***

The nurse's professional skills are based on expectations that society, patients, relatives and colleagues put on her. Her own expectations of how professional skills should be seen in daily life also influence her work and professional development. The nurse in the Chinese context where this study took place is neither expected to comfort patients nor to take care of the patient's basic needs, such as nutrition and hygiene. These needs are the relatives' responsibility and are not seen as a part of professional nursing care. The nurses are supposed to keep a distance to the patients, and are not expected to discuss intimate and personal matters with them.

The following patterns emerged regarding the obligation to act with professional skills and within the tradition:

1. Professional nursing care practices requires a professional attitude and skilled care practices.
2. Professional nursing practices are within a curing paradigm rather than a caring paradigm.
3. A professional nursing care practice is keeping distance to the patient and letting the care be led by the family and the patient.

4. Supervision is a good practice in preparing nurses for professional nursing care.

**Professional nursing care practices requires a professional attitude and skilled care practices.**

The nurses struggle with being in-between the patients and the relatives, in-between the relatives, patients and the doctors and in-between an old tradition and a new profession when doing their daily job. Traditions and professional skills are not contradictions; by knowing traditions the nurse can through her professional skills uphold and enhance traditions and restructure old traditions to fit into the modern daily life at the hospital. Nurses view their profession as multidimensional, and an important tenet in the nurse's profession is to be confident. The nurse has to be strong and not let any insecurity be shown, since the insecurity will spread to the patient, and they will consequently lose their confidence in the nurse's professional capability. It is not appropriate to lose control: the nurse has to be the strong one, and only show positive feelings which create a positive attitude in the patient. Below is a quotation from a discussion with a nurse. The discussion shows the professional care practice concerning confidence aiming at alleviating suffering. The words in brackets and with normal font are the authors clarification of the topic discussed.

*Yes, it [alleviation of suffering] is to give the patient confidence. If you are insecure as a nurse you give insecurity to the patient. (Nurse.)*

A professional care practice is to give the patient confidence, and this can be done by acting in a confident way when meeting and treating the patient. The nursing care I have seen at the hospitals can be categorized as task oriented. The nurses often mention the task they carry out, when describing their job. They describe dress changes, control of vital signs, injections, infusions, educating patients and relatives and following doctor's orders. To have good technical skills is described as necessary for a nurse. The nurse's perspective seems to be based on a biomedical viewpoint which is demonstrated when the nurses describe the importance of having medical knowledge and technical expertise to work effectively. The nurses describe the care as consisting of more technical and mechanical care than holistic care. They nevertheless find a holistic model important, which is visible when they discuss the importance of having a patient lead education, based on patients questions and information concerning the patient's situation, such as information about the disease, special diet required, and so on. The nurses find effective nursing care practices important in alleviating a patient s suffering. As described above it is important to assure the patient

confidence, and the patients feel security when they are measured by machines or getting IV drips or injections since it is a sign of a professional care. Below is a quotation with cultural care descriptors that points out the importance of technical skills in nursing. The cultural care descriptors are in bold letters.

*The nurse may not give suffering to the patient. I think every patient needs that the **nurse has the advanced technology... The patients believe in the technique and feel safe when they are measured by different machines.** (Nurse.)*

The quotation above shows the nurses' and patients' belief in using technical measurements and technical nursing methods. This defines the nurses' purpose as being task oriented, since the technical measurements and treatments ask for such an approach. Technical knowledge is linked to alleviation of suffering. The task-oriented approach and biomedical viewpoint is also described by patients when referring to the nurse's job, and their relationship to nurses. Some of the patients see the nurse as professional and link this to willingness to help and support the patient, to show a good attitude (smiling, being kind). Good nursing skills are also mentioned. Other patients describe the nurse as hard working with no time left over for the patient. The patient does not want to disturb the nurse and is even afraid of her (nurses have a bad attitude towards patients, nurses are angry with patients when they disturb her). No patient or relative say that the nurse has limited or bad technical skills, rather the reverse - they praise the nurses technical skills. The relatives see that that the nurses mostly work with technical things.

When working with a task-oriented approach based on a biomedical model the patient's needs for treatment is met. The patients coming to the hospital may have to wait several hours for an examination but the examination will be done the same day. This is a way of showing respect for the sick patient and confirming his or her need for care. According to the doctor quoted below, they maintain this routine in order to give good service to the patients and to avoid complaints from patients. One of the doctors describes the situation at the x-ray department as following;

*...because the patients are traveling a long distance to the hospital and they are anxious, need a fast examination, and beside other things the patients maybe have to rent a room close to the hospital and this gives extra costs to the patient. So we consequently have no waiting list, no booked time we are just working until there are no more patients waiting for x-ray. (Doctor at x-ray department.)*

Several similar situations are seen regarding the attitude towards the patient and respect for the patient's need for care, both among nurses and doctors.

### **Nurses uphold a curing paradigm rather than a caring paradigm**

The nurses I have met in PRC tend to uphold a curing paradigm based on the biomedical model where technical skills are highly appreciated, as described above. The goal for hospitalization is the patient's curing and caring is not mentioned as a goal; caring for the patient aims at curing the patient. The nurses are not fully satisfied with the existing paradigm, since they also mention the patient's need for care. There seems to be little time or space for creating a paradigm where caring is in focus. The model used by nurses, supplies them with techniques for tasks related to physical pain, medication administration, and patient education. It does however not necessarily show techniques for individual emotional support for a patient. The nurses can see a need of individual emotional support but are not prepared to fulfill it. The nurse wants the relatives to deliver emotional support, such as comforting the patient and the nurses' task is to support with medical methods if the situation is not getting better. When talking about comforting patients, nurses generally mention situations where the patient is in pain.

This situation is not completely satisfactory for the nurses, but they are trapped in their own cultural values, according to which a nurse is not supposed to have a caring paradigm. She is supposed to be professional, and caring features have less importance compared to curing features which create the curing paradigm. This is a contradiction since the patients appreciate nurses who support them emotionally. Patients are reticent towards nurses who seem to be in a hurry and they do not want to disturb them. The nurses are equally unsatisfied with the situation as it is today. One of the nurses describes this paradox in a few words quoted below. The contradiction is in bold letters.

***When I cannot alleviate pain, as a nurse I feel so uncomfortable.**  
I cannot alleviate or relieve pain. **The nurses should cure the patients.** (Nurse.)*

The nurses recognize the patient's need when pain is not alleviated, and pain-killers do not always alleviate the pain. The patients should be cured, and when this is not possible it raises feelings of insecurity and even helplessness. The curing paradigm keeps the nurse from developing a caring paradigm. Many patients will never be cured, but they need to be cared for in order to live a good and satisfying life.

Technical skills in nursing are highly valued and appreciated and are important parts of the nursing student's theoretical and practical nursing education. Technical skills are defined as administering medications (IV- and other injections), managing computer systems, and wound dressing. Basic nursing (including patients' hygiene and nutrition) is not as highly appreciated and this is evident when the nurses evaluate their job, and compare different tasks. Basic nursing is seen as heavy and dirty; a job which does not demand a high level of education. Technical nursing actions are on the other hand appreciated since they require education, which is seen in the quotation below.

***Basic nursing is not fancy, there is no technology in it and it is dirty. Many nurses think it is time consuming and the nurses feel tired after basic nursing. (Nurse.)***

The university hospitals are well equipped with many modern diagnostic tools. This gives the opportunity for the clinicians and surgeons to make more accurate diagnoses and provide better medical services to the patient. In contrast, basic nursing care suffers from lack of modern facilities (little space for personal hygiene, and for example no technical equipment for lifting bed-ridden patients was observed). Technical solutions to health problems are also highly valued; the patients and the relatives ask for intravenous injections when in need of effective treatment, while oral medication is seen as less effective. Almost every patient at the hospital has an IV-drip, which can be seen in the following quotation.

***The patients want to have IV-drip to recover faster, few patients take oral medication. (Nurse.)***

The nurses have to be skilled in how to administrate intravenous injections. Intravenous injections the needles are short and used only for one medication dosage. The next time that medication is given a vein is perforated again. The patient is usually left without the nurse's supervision since the intravenous infusion is supervised by the patient's relative or Hu Gong who alarms the nurse when the bottle is empty or if the infusion is giving side effects. Injections are also seen as more powerful than oral medication, and medications are more frequently administered through injections than orally.

**A professional nursing care practice is keeping distance to the patient and letting the care be led by the family and the patient.**

The observations show that nurses uphold a distance to the patients. The distance can be seen as a way of keeping the social norms of not interfering with

a stranger such as the patient, but it can also be seen as a way of letting the patient guide the nursing care a way of following the patient's needs. This can be seen as a traditional way of caring for patients. To uphold a distance does not indicate lack of care for the patient, it can instead be interpreted as a way of letting the patient endure and of not bringing the patient into emotional suffering which will embarrass him/her. Nurses do not take over or influence important decisions regarding treatment or the patient's overall situation; they act together with the relatives. Nurses encourage generic health care through their attitude, and they use the strategy of educating the relatives in order to help the patient to recover. The nurses accept the inconvenience of huge amounts of relatives at a ward, although this creates special risks in the professional job, such as the spread of infections and nurses' lack of control of professional nursing procedures. The nurses act within the traditions. They therefore accept and find ways of working with relatives for the benefit of the patient instead of excluding the relative's influence on the patient's care.

The distance can be seen as a gap between the nurses and the patients and the counterparts view the gap differently. Some of the patients state that they do not want to disturb the nurses unless necessary, and this can be interpreted as the patients being afraid of the nurses. However, the nurses feel that they are open to meeting the patient's caring needs, but that it is difficult to find the correct methods. This problem is mostly discussed among young nurses participating in the study. One reason for this can be that the young nurses are not experienced and methods to develop a caring attitude are not discussed in nursing education, but another equally important explanation can be that it is not expected that nurses comfort patients and therefore it is not a part of the nurse's daily life to show direct support. This gives the nurse a feeling of not "caring enough" and not "being good enough". A nurse describes such a situation, when caring for a patient with a severe disease as follows

*The patient had cancer in the liver and **I think I will never forget him**. When he asked me how to achieve health **I didn't know how to answer**. **I hope I could do something for him**. For him every medication was useless, I think he was suffering. **I wanted to change the situation and make the patient smile but I couldn't**. (Nurse.)*

In the quotation above the cultural care descriptors are written in bold letters. The nurse in the statement above was aware of the patient's suffering and need to be cared for, but the cultural value of not getting too close to the patient and also the principle of no disclosure of information could possibly have caused an obstacle for the nurse to find a way to act and react. The nurse is not sup-

posed to get too close, and touch is not commonly shown as a comforting act. In the quotation above the statements concerning the nurse's experienced shortcomings are in bold print. In the quotation below the nurse's professional care practices are outlined describing the expected outcome and also the shortcomings.

*We use touch, we want to comfort the patient. We must take care of the patients emotions, you can see on the patients facial expression whether he want to be touched, if the patient feel like you don't want to touch him then you cannot.... You know **if I have a patient, a male patient he will feel tension while I touch him. I feel embarrassed too.** (Nurse.)*

In the statement above the nurse describes the "will" to comfort the patient, and she can see the need for touch as comfort for the patient, but the tradition prevents her from indulging in this kind of caring act. According to the informants it is not proper to touch a male patient if the touch is not professional. A professional touch is, according to the informants, linked to technical manoeuvres of the nurse's job. The nurses are not prepared to get close to patients. The nurse's task is to help the patient to endure the situation and not to suffer emotionally in public. The nurse should not bring tension to the patient; harmony is the optimal goal for the nurse in the relationship with patients.

### **Supervision is a good practice in preparing nurses for professional nursing care.**

The nurses feel a need for supervision and guidance in order to be able to carry out daily work, as well as to comfort and meet the patient with kindness. The nurses are faced with great difficulty when seeing the need for comfort, seeing but not having the capacity to fulfil this need. The supervision of young nurses at the wards mostly consists of technical matters. Helping the patient to control him or herself is a task which is often mentioned by the nurses. In a group discussion, one nurse described a situation where a man was "overly happy" and in order to calm him down, his father-in-law gave him some bad news just to get the man back to his senses, so that he would not continue to overreact with happiness. It is not common to show emotional suffering and the nurse's task is also to help the patient to control him-self. The quotation below shows the cultural care descriptors concerning control and helplessness in bold letters.

*And when a person is suffering from the vastest pain in his life so that **he can't control himself**, I'll do my best to help him, but it seems useless and **then I feel that I need help too.** (Nurse.)*



The guidelines for how to act are not clear, and the Western nursing models, mentioned by the nurses as being the nursing models used in nursing care do not give much guidance in this matter since the cultural values are different. The PRC is also a country where signs and symbols often stand for messages about caring needs. The nurses are aware of the need for a holistic approach in caring for the patient, even though the physiological and educational approach is dominating. The nurses did not further explain what a psychological approach is, but one interpretation is that it can be defined as an approach where emotions are clearly visible and where the patient can get support for working through a difficult situation. The psychological approach also includes the nurses having harmony which gives them the strength and possibility to transfer this harmony to the patients. However the distance to the patient is always there. Nurses in a group discussion describe the psychological approach in the quotation below. The cultural care descriptors are written in bold letters.

*It is the relatives that decide when to talk to the patient about a disease. **We need to have a psychological approach in our care for the patient.** If we tell the patient we push him down to earth. If the patient know that death will come we have to control it even if we don't have methods to cure them **we have to be strong to stay, be strong psychologically, we have to care for the body to make them feel better.** (Nurse in a group discussion.)( sic.)*

The nurses link the body to the mind and a strong body helps the mind to stay in harmony. The nurses emphasize the important professional task of supporting physical health in order to increase the harmony of the patient.

The nurse's way of bridging the gap between the patient and the nurse is through relieving pain but also through matters such as education, information, and trying to understand the reason for the patient's suffering. The nurse often asks the relative to assist in relieving suffering, a fact explained further below. To care for the body, to supply the patient with prerequisites for healing and to feel wellbeing is important. This gives the patient strength to deal with a difficult disease or a disease that will change the life conditions of the patient. The relatives support the patient's mental and spiritual wellbeing.

The nurses also express their feeling of not being able to take control of nursing care because of relatives. The relatives can make wrong decisions regarding treatment due to their lack of knowledge, and the nurses want to have a greater influence on the nursing care for the benefit of the patient. Nurses express that

sometimes they feel that the relatives obstruct the nursing care, but they nevertheless count on having a relative or Hu Gong present, to take care of the patient's basic caring needs. The nurses are aware that the relatives or Hu Gongs" are not educated for the tasks they are given and this is difficult for the nurses. They have to educate the "Hu Gongs" as they are working in an environment in which special skills are needed. Below is a quotation from a discussion with nurses. The cultural care descriptors are written in bold letters.

***It is not only bad to have relatives at hospital ...It is the tradition... It is the traditional way ...Sometimes the relatives interrupt the job...As a patient it is good to have all around you, but as a nurse it is not good having so many around in the ward. It interrupts our job also sometimes when they show their needs, about **expressing their feelings, they need their relatives**...If there are many, many operations and **the staff is working very hard, they give the job to the relatives**. Generally the relatives cannot do this job...We have them (Hu Gongs) at ICU, they wash the patient, they are employed by the hospital, and we teach them...**The relative's role is to comfort the patient and the relative is there because of the social environment, it is something both for the patient and for the nurse.** (Nurses in a group discussion.)***

The relatives have the possibility to influence the care given due to the nurses' fear of complaints. The nurses have to follow the social norms, and on the one hand care for the patient, but on the other hand not have full control over the care. Regardless of the paradoxical situation, the nurses have to act professionally and support the patients' care. If the relatives are not satisfied, they can complain to the administrators, who seem to more frequently choose the relatives part in such conflict. This is at least the picture the nurses give about this kind of situation.

### ***Communication – a caring act***

The nurse communicates with many different groups of people every day. The patient and the relatives are in focus, but the communication between the doctors and nurses is also important when planning the care of the patient. The nurse participates in meetings with the medical staff of the unit and the care is planned for all patients. When asking the nurses if their standpoints regarding the patient are taken in consideration when discussing treatment the nurses feel that their voices are heard, but the direct contact with a specific patient happens between the doctor and the relatives. The nurses document everything con-

cerning medical treatment carefully, but nothing personal (such as the patient's mood, co-operation, questions, and information given to the patient).

Education and information is a task often referred to by the nurses and also seen when observing the nurses job. Informing and educating patients and relatives is a professional care practice aiming at easing the patients' and relatives' situations. The nurses communicate through education and information. Information and education take time, and according to observations as well as nurse's and patient's statements, education is done in a meeting between patients, nurses and relatives. The education is done naturally and through observations one sees that the nurse always informs the patient and the relative about something when talking to the patient. The nurse needs to have enough time for proper information, and this is not always possible due to many tasks and a busy working-schedule according to the nurses' statements. The nurse explains to the relatives how to care for the patient, and explains to the patient what is going on. Based on observations, the patients did not ask much about nursing care but the relatives asked about the care given and how they should support and care for the sick relative. Although I did not see any patient questioning a nurse about care, the nurses base their education on questions from the patient. The nurses work in-between patients and doctors, which can be seen when the nurse explains to the patient what has been said on the doctors round. The patient has many questions and the nurse tries to explain and clarify matters concerning treatment and disease, but always within the frame of what the patient knows, should know and does not know.

The following patterns were seen describing communication as a caring act:

1. Communication with patients and relatives is an important professional care practice which reflects attitudes in nursing.
2. Educating patients and relatives is a professional care practice.
3. Caring for patients through the relatives is a professional care practice.

The different patterns are described below and illustrated by with quotations from the patients, relatives and nurses.

**Communication with patients and relatives is an important professional care practice.**

It takes time to get to know people in China, and communication is seldom direct. The Chinese patient is unobtrusive, but the nurse can sometimes find

a space where communication is possible. Below is a statement about communication at a hospital. The statement about the acts of communication is in bold letters.

***It takes time to get to know people in China. If you have problems you first talk to your relatives and friends and then they tell the nurse. There is seldom direct communication. It takes a long time to learn to know each other but sometimes you can find a space where you can talk to each other, a space where you can feel safe and secure.***  
(Nurse.)

One professional care practice is to create the “space” where communication can take place. “The space” is also mentioned by nurses when asked about comforting patients. One nurse describes the space as a “place” where she can touch the patient without getting embarrassed and without embarrassing the patient. Commonly the private space is shared with the relative and family and not with a nurse, but in situations where the nurse has to enter the patient’s private space she has to be prepared. This kind of situation can occur when the patient is suffering emotionally in public. To be forced into emotional public suffering is a violation of dignity among Chinese patients; all acts of forcing an unwilling patient towards something are considered unethical. The nurses are very careful with information about a severe disease, or news that can create emotional suffering or awaken feelings that the patient cannot control. People do not want to show feelings in public, since they do not want to lose face but keep control over life and situations. It is an important professional care practice not to force the patient into emotional suffering.

Nurses view communication as a social part of their job, and they build their understanding of the patient’s need for care through communication. Communication is also seen as a method for showing care and awareness of the patient’s and relative’s situation. The nurse’s attitude is important when communicating with patients and their relatives. This is expressed both by nurses and patients in this study. The nurse has to have a positive attitude to be able to bring harmony to the patient, and this is seen as acting professionally both by nurses and patients. The positive attitude is described by patients as the nurse always having a smile for the patient, always observing the patient and his/her caring needs. Below is a quotation of a nurse who describes the importance of the nurse’s positive attitude in caring for the patient. The professional care practices are marked with bold letters.

***The nurse’s attitude is very important to a patient. If nurse always***

*smile speak lightly take more care of the patients. I think the patient will move and feel better. As a nurse I must tell the patient's relatives to look about him as often as possible. No one want to be abandoned especially the patient. Use some anodyne, massage the pain place, and distract the patient's attention. (Nurse.)*

The patients describe a good nurse as having a good attitude, including greeting patients, speaking with a gentle voice and meeting the patients with a gentle smile. The patients are sensitive to the non-verbal communication behaviour of nurses, and the nurse is also aware of that. The patient does not want to approach the nurse if the nurse's attitude is not welcoming. Several informants (patients and relatives) describe situations when the nurse is in a hurry and does not seem to welcome an approach. She is consequently not capable of seeing the patient's need for care. The patient does not want to disturb the busy nurse.

The encouragement of patients is also conducted through communication. The nurse is supposed to help the patient to achieve and uphold harmony. Harmony can be increased by a positive attitude, and the nurse should be able to give harmony to a patient in disharmony. Below is a quotation with the professional care practice in bold letters.

***The nurses try to encourage the patient to keep in good mood. They try to discuss interesting news or other matters of concern, like teaching the patient about the disease. It is important that the nurse tries to keep the patient in a good mood. (Nurse.)***

The nurses encourage the patient to stay positive and they do it by discussing and answering the questions that patients have (teaching the patient), by showing facts through signs and symbols (like caring more for a patient who is seriously ill, giving him or her the extra attention needed to raise questions about the disease). Distraction is also a technique to help the patient through difficult times; it diverts the patient's thoughts from the disease and suffering. To be in a good mood is to have harmony, to have disharmony is associated with emotional suffering. Based on patients', nurses' and relatives' statements there is a contradiction in communication concerning illness, disease and treatment. The patients are not supposed to get much information concerning the disease and the doctor is the counterpart in that communication. The patient would like to get detailed information, but wants the relatives to get the information first. When the patient gets detailed information about the disease his/her harmony can be destroyed, and harmony is a very important value in Chinese nursing.

The nurse has to have multiple skills in interpreting and understanding the non- visible signs of the patient's caring needs, in order to understand what, to whom and how information is spread. Information about a disease is given to the relatives, usually by the doctors. The nurses through education and information try to help the patient to stay positive. The communication leading to harmony can be designed in two ways to achieve two aims; to educate the patient and the relative or to distract the attention of the patient. To be in harmony is important for the patient as well as for the nurse.

**Educating patients and relatives is an important professional care practice.**

To educate and inform patients is a way for the nurse to build a relationship with the patient and his/her family. It is mentioned as one of the most important parts of the nurse's task to carry out a good professional care practice. The nurse knows the facts about a disease and treatment, and the patient gets the information by asking questions. None of them has to discuss facts about the disease if none of them is ready to take that step. It is like a drama where the actors know their roles. The patient asks questions that he or she will get answered and the nurse bases her information and education on the questions asked. The doctor is the main informant but the nurse is the main educator.

It is an important responsibility to be well informed when working as a nurse and the nurse has to give correct information to all counterparts in the caring relationship, to the relatives, colleagues and doctors. The education is based on a diligent search for information about the patient and the patient's situation; health, family situation and socio-economic situation. The nurse may not give erroneous information; that would lead to a conflict. This is an interesting contradiction. The nurses are neither allowed nor expected to tell the truth to a patient about a serious disease, but is expected to give truthful information. If the information is wrong, it will lead to a conflict which is not acceptable due to cultural values (like striving for harmony). Some of the patients know about their disease, others do not. The information has to be adjusted to the patient's specific situation. Good information and education about a disease helps the patient to co-operate with nurses and doctors during treatment. One of the professional care practice is to educate the patient based on the patient's questions and to let the education be lead by the patient.

Nurses also see information and the subsequent education as one of the most important techniques to relieve anxiety. The nurses acting as informants point out the importance of the patient's feeling of being welcomed to the ward. That is the first step in alleviating anxiety for the patient. Information about the ward

helps the patient and the relatives to adjust to a strange situation and find their way to deal with it. Below is a quotation from a group discussion about important professional care methods which concern education. The statements concerning how to educate (professional care practice) are written in bold letters.

*...If you don't know anything about the patient and the disease how can you then educate? **Before you educate patients you have to know, especially about the patient the family the disease, everything you have to know.** If they ask you questions and you don't answer them properly also make problems ...**You also have to inform the relative** all about the patient, some of the relatives may agree with the doctors ideas but many of them don't agree, they complain, "you didn't tell me about the operation" so now especially today **the doctors and the nurses we have to tell to the relatives, every relative** ...It is important to know it, maybe the relatives get angry, it is the **nurses social job to inform the relatives.** The nurse's social job is important ...The Chinese patient as we know when admitted to the hospital many of the patients don't know the nursing care, they don't know about the health problems and disease...**we always have to explain to the patient what shall we do for next let the patient understand us and then co-operate with us.** In our job we always must explain to the patient that is very important to us we must always co-operate, we must let the patient understand... I think first of all we need to **have enough time to stay with the patient and to talk with the patient.** I think after the doctors round the patients have a lot of questions about the disease how to choose the healthy style of living. I think as the nurse we need to have time after the doctors round we just can ask the patient "what do you want to know?" they need to talk then we come to the questions when we can find out, and we show the knowledge and can tell the patient...Some patients totally don't know what this disease means, some patients ask, it depends much on the patients education level. They don't know what this disease means. **I think that the Chinese culture if the patient is having the cancer or another heavy disease, nobody want to tell the patient,** so we have different patients, patients who know nothing about the disease and the treatment, they just want to know, they don't show their own appearance, it's essential, you know they see other patients having the cancer and then they have their stone period **ask themselves, maybe I have it.** Then they start to ask the doctor and the relatives and the nurse and they ask what is the treatment and what is the time for life... **they now have started to want to know. They perhaps feel that***

*they have the right to know...We need to educate them about healthy life. We only need to get information to them, that they need to go to chemotherapy...so we treat the patient well how to take the blood samples so we need to show the patient ...we maybe just tell the patient a little bit, about some changes...I think, I work in this blood cancer ward, with chemotherapy so that you show I ask the patient, we have a book at the ward with some information, it tells something to the patient about the disease. **You shouldn't give too much information, because that affects the patient,** much information is about the medical part, **just give the patient general information** about the disease, not going to use the medical explanations. (Nurses in a group discussion.)*

Based on the statement above one professional care practice is to learn to know the patient and his or her family. The nurse needs to have enough information about the patient and his or her situation, as well as enough time for conducting the education. The knowledge is used when informing and educating the patient and the family. The knowledge about the patient is formed by information from the patient the relatives and also from the doctors. Another professional care practice is to give tailor-made answers. The answers are formed based on the patients' and relatives' insights and how receptive they are to information and education. This care practice forms the basis of a patient lead practice. The information is delivered indirectly, with specific concern, through signs. This prepares the patient for the information and opens up the possibility for the patient to ask questions. The doctor is mainly responsible for the information about a disease and treatment, but the nurse is also expected to give detailed information about the disease and treatment when required. This information is also based on the patient's questions.

The education consists of information about how to conduct and monitor the treatment (among other things IV drip, personal hygiene, emptying urine-bags, administering medication, treatments) and facts about the disease ("what is" the disease). The relatives need to know everything about a disease and treatment to be able to make the right decisions. It is also important that the relatives understand the importance of for example a special diet (like if the patient has diabetes and the relatives bring food for the patient). A professional care practice consequently aims at assuring the level of the relative's knowledge about (nursing) care procedures (which are supposed to be carried out by the relative). The nurses spend a lot of time educating patients and relatives. A Hu Gong, who acts instead of a relative, is rarely seen in discussions with nurses regarding a patient's disease or treatment. The Hu Gong gets the information



from the patient, the relatives or from the doctor, and according to the informants the Hu Gong just gets same information as the patient. Nurses see the patients' and relatives' information and education as a social part of their job, and the higher level of their knowledge, the better informed they are the better the co-operation with doctors and nurses.

An important professional care practice is to ease anxiety. The anxiety that emerges when a patient is admitted to the ward is relieved by information. The patient should feel welcome and at home, otherwise it is difficult to co-operate with the patient. The nurses address the frequently occurring problem of patients arriving to the hospital in bad condition. The patients want to stay at home as long as possible due to the high costs of hospitalization and therefore the patients are often in a bad condition when arriving to hospital. They have to stay for a longer period than if they had come at an earlier stage of the outbreak of the disease.

**Caring for patients through the relatives is a professional care practice.**

The relatives are a natural part of the environment at a ward. The relatives have responsibility for the basic nursing care. The relatives can be seen as "enablers"<sup>50</sup> to help the patient to heal and one of the nurse's professional care practices is to adjust the information and education for the relatives so that the relatives through it can help the patient to achieve harmony. The nurse shows her concern for the patient by encouraging the relatives to visit him or her. A lack of visitors awakens the nurse's pity, but she cannot fill the empty space. The relatives might abandon the patient due to economical reasons or other reasons such as problems with caring for the patient due to the nature of the disease (for example patients with Alzheimer's disease or patients with infectious diseases). The nurses are aware of the relatives' shortcomings as professional caregivers and that they need supervision in how to act in the patient's actual situation. The relatives have to take over parts of the nurse's job and it is the nurse's responsibility to educate the relatives so they can do it. A nurse explains it as follows;

*If there are many, many operations and the staff is working very hard, they give the job to the relatives. Generally the relatives cannot do this job. (Nurse.)*

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<sup>50</sup> "Enabler" is a concept coined by Leininger and used in her description of an ethnonursing method (1991, 1995, 2002a, 2005b). The concept "enabler" is borrowed as a description of a situation when discussing the relative's role at a ward meaning that the relatives can facilitate the patients to co-operate with nurses and doctors aiming to cure and heal the patient.

The nurses appreciate the relatives staying at the ward and they can see that the relatives can help to create a positive attitude and through this also speed up the healing process. But nurses also feel that the relatives can disturb the job, due to lack of knowledge. Education of the relatives is an important nursing task as described above. The relatives can also be an obstacle for nursing students, according to the informants. The nurses have to work with the relatives and educate them and this takes time from educating nursing students. The nurses have to be able to rely on the relatives when they take over parts of the nurse's job. Below is a quotation showing the nurses' view of having relatives at a ward. The cultural care descriptors are written in bold letters.

*It is good to have relatives in the wards. It would quicken the healing process and help patients to **build positive attitudes**. But on the other hand some **relatives disturb nurse's work due to lack of professional knowledge**... **The relatives have two functions, to take care of the patient and to show their concern**. (Nurses in a group discussion.)*

The nurses agree on the importance of having a natural caregiver present at the hospital. When the patient feels secure positive and cared for, the healing process speeds up. It is the relatives' generic care practices that convey the feeling of being cared for. The relatives are present at the ward all the time and regardless of the rules that limit the number of relatives (to only one per patient), there are several relatives present. The nurses want the relatives to stay, since this coincides with the cultural values, but the relatives can also be seen as obstacles in the nursing care, if their demands are perceived to be unrealistic. The relative's demands carry weight and must be considered. The nurses do not want the relatives to complain since the hospital leaders will blame the nurse for not doing her job well; which then becomes a form of losing "face".

The nurses see the difference between the nurse's task and the relative's role. The relative is mainly at the ward for comforting and keeping the patient company. The relatives can take care of basic care (nutrition, personal hygiene) without education, but when they have to monitor IV-drips, temperature, empty urine-bags, assist in different treatments and bring food for patients with a certain diet, the nurse needs to educate the relative first. The nurse's education of the relative consists of information about the disease, and about how current nursing tasks should be conducted. Patients feel more secure when relatives are present, which can be seen in the amount of complaints; patients complain more often when the relatives are present. The relatives give them the courage to complain. The relatives consequently can act as a guarantee for good care.

The relatives might also complain about treatment and the results of care. Their complaints may not be relevant, but they have to be handled. This situation is negative for the nurse since they have difficulty defending themselves against relatives. Below is a quotation from two nurses showing the nurses double role when working through and with relatives. The relatives' and nurses' roles are in bold letters.

***You can ask the relatives to help with the care and they also want to help in the care. The relatives are more like a support for the patient, to comfort and make them feel secure, the relatives don't need to do basic care but they want to....When the relatives are here the patient is complaining much more, if the relatives are not here the patients don't complain so much. The patients want to get comfort and attention from the relatives. The nurse can assess the patient's pain in several different ways and decide about the medication. The nurses can ask the relatives to comfort first and if it doesn't help then they can give painkillers.*** (Nurse.)

The nursing care practice is to work with and through the relatives in order to facilitate the nursing care and if possible to cure the patient. The nurse invites the relatives to take part in the professional nursing care and the invitation can include pain assessment and alleviation of pain. The nurse interprets signs concerning the cause of a patient's pain - is it due to the disease, treatment or anxiety? The nurse can begin by asking the relatives to comfort the patient, since the family's comfort will help if the pain is influenced by anxiety, fear and worries. However if the family's comfort does not alleviate the patient's pain, then painkillers are needed.

### ***Helplessness and hope – the different faces of suffering***

Illness and suffering forms the context of life in a hospital. When asking nurses to explain what suffering is; how they see it, and what feelings it awakens inside themselves, they describe it as influencing the whole human being. Suffering is always present at the hospital. The patient suffers, but is not the only sufferer. A patient's illness and disease influences the relative and the nurse as well. Suffering has many different faces; the nurses describe suffering caused by pain, disease, mental problems and social circumstances, and the patient expresses the suffering differently. Suffering is described as a private, individual experience. Existential suffering is described as the fear of death. To alleviate suffering and to help the patient to achieve harmony are important professional nursing care practices. Hope is an important part of harmony. It is seen in the

patients' and relatives' description of how they experience hospitalization and the outbreak of a severe disease. White lies are accepted when the aim is to preserve hope for recovery and to save the patient from worries.

The following patterns were seen regarding helplessness and hope in relation to suffering.

1. Suffering affects the whole entity of the patient and the family and affects the nurse as well.
2. Letting the patient's suffering be a family matter is a professional care practice.
3. Encouraging hope and seeing it as an antidote for suffering is a professional care practice.

The different patterns are described below and illustrated with quotations from the nurses participating in the study.

**Suffering affects the whole entity of the patient and the family and affects the nurse as well.**

Suffering is seen as a part of human life. It will affect everybody at some point. A holistic approach can be seen when discussing suffering. The human being is viewed as an entity and suffering, regardless of cause, affects the whole person and his/her family. Suffering can, according to the nurses, be caused by physical pain, psychological (some nurses call it "mental" and their definition of "mental" and "psychological" are similar) and social circumstances and can be said to represent disharmony in the body and mind. The human being is in interaction with the environment. Diseases can, according to TCM, be caused by environmental circumstances like the weather. According to TCM it is important to document the environmental circumstances of the moment when the patient became ill, since they influence the care for the patient. Suffering is described as personal; it is within the person's mind and body, and the informants do not attempt to ascribe suffering a meaning, it is seen as evil and no good comes out of it. Below is a quotation from a nurse in which the description and the causes of suffering are written in bold letters.

***Suffering is a part of human life. It will happen in any time and part or aspects of body. The human being is whole. Moreover the human being is influenced by the exterior environment. So suffering can be caused by three reasons; physical, psychological and social. And any of three reasons would influence each other. In the theory of***

*TCM when the whole human being and the exterior environment are in the disharmony stage that will cause suffering. (Nurse.)*

There is, according to the informants, a difference between pain and suffering. Pain is mainly described as physical nausea or discomfort, however suffering covers a larger area of distress and the discussion about what suffering is and how it is viewed among nurses gives the impression of a concept seen in many ways. Suffering caused by social circumstances such as lack of money or loneliness are just as important as the suffering caused by pain from a disease, but more difficult to influence. Below is a statement from a nurse who describes situations where a nurse cannot alleviate suffering. The different reasons for suffering are in bold letters as well as the nurse's experience of not being able to alleviate suffering.

*If the **suffering is the physical pain** caused by disease but the disease can't permit us to use some medication to relieve the pain, **I think I have no ability to alleviate the suffering**. Sometimes if the patients' themselves don't know the reasons for the suffering I think what I can do is to find the truth but sometimes I have not the ability either. **If the patient's suffering comes from the absent of money or other expensive things I think I have no ways to help them**. **If the patient's suffering comes from the loss of work or other social pressures like this I can't help them either** but when I met these situations **I felt sorry about them**. (Nurse.)*

The nurse is aware of situations where professional nursing care cannot alleviate suffering and the nurse is helpless in these situations. The nurses describes it as "feeling sorry for the patient", "the nurse suffers too". The nurse's suffering is due to the feeling of helplessness when it is impossible to influence the situation. If the disease is severe and no painkillers can alleviate a physical pain then the nurse is helpless, and the nurses then think the family should comfort and try to alleviate the pain. The nurse at that point invites the relative to participate in the care, or the relatives invite themselves into the care. The informants describe suffering as affecting the whole human being, it is suffering in both body and mind with complex dynamics of pain and worries. The physical pain can commonly be alleviated with painkillers, but mental suffering and suffering caused by economical problems cannot be alleviated with medications, these have to be dealt with in the family and the nurse can just be an observer, since there is nothing she can do.

The suffering caused by social circumstances is seen as worse than suffering

caused by physical pain. “Social suffering” is difficult to handle and the nursing staff can do nothing to help the patient, the suffering caused by social conditions has to be relieved by the patient him/herself together with the family. Suffering caused by economical problems affects the whole person since the lack of money prevents the patient from getting care. Commonly the extended family help out and the sick family member can get cared for, but this is not the case for everybody. This influences the whole person and the social status of the person, and feelings of shame, guilt and a lost of dignity occur. Below is a quotation from a nurse about suffering due to economical problems. The culture care descriptors showing the signs of economical problems among patients and nurses interpretation of the patient’s situation are in bold letters.

***If the patient is suffering from economic problems they get everything from his family and friends. They don’t want to explain that they need money I think this is the Chinese peoples mind. The patients don’t want to talk about it, but you know when the patient asks us to not use too expensive medications then we know. The patients know that they have to pay it all. Some patients can tell the nurse at the admission to the hospital that they don’t have money to pay. If no relatives visit the hospital then we know.... We cannot talk about money problems before we know the patient. If the patient cannot pay we need to fill in a form and ask the head nurse from administrative department to allow us to sign the paper*** [that allows the ward to give medical treatment without charging the patient.] ....  
***If it is an emergency we don’t know who the patient is and who has sent him then we have to care for the patient, but at a medical ward when we will have the patient for a long time then we learn to know the patient. Every day we have the paper for what medicine is given and how much it has coasted and sometimes the patient sees this paper and he know that this medicine is very expensive and then they ask us to not use this medicine to use another medicine that has the same effect The patient may have pain and when we ask if the patient needs painkiller the patient may ask “How much” and then he says no then we know he has economical problem. When the patient get the IV they ask us to let all the water in the tube go in. They ask us to drop all of the water so we know that they have some question in their economy. We try our best and in some really crisis the head nurse says that we can ask the director of the hospital to sign the permission for CT or MR for the patient. Some of the patient gets the money by themselves and some patients have not even money to get home, 2 yens for the bus. (Nurse.) sic.***

The patient's economical status is seen in the daily care for patients. If the patient does not have a good economical situation the patient not only has to worry about his/her disease, but also about the costs at the hospital. Not only the patient worries, the family carry the worries until the patient is prepared to face all the facts. But a husband, a son, a man always worries about hospital bills, since he still has the responsibility for the family and he is the one that pays the hospital bills. The patient's economical status is a family matter and it is not possible for the nurse to ask if the patient has economical problems until she knows the patient very well. The nurse interprets signs and prepares herself for the problems that will arise when it is clear that the patient has difficulties to pay the treatment given. The patient has to pay for everything at the hospital, the bed, the food, the medications, treatments and so on. The highest costs at the hospital are mainly based on treatment (such as surgery) and medications, and the relatives and/or the patient have to follow up the costs for medications and avoid using too much and too expensive medication. The patient does not always trust the doctors and they have good reasons for this. The hospitals do not get enough money from the government to run their practice. The hospital has to be independent and especially if the hospital wants to focus on research and development, money must come from patients. This creates situations where the patient might get abused. The suffering caused by social circumstances is seen as worse than suffering caused by physical pain. To not have money enough for hospitalization is shameful and the patient does not want to talk about it.

In very special cases the doctor and the nurse can write an application to the hospital leaders to waive a patient's care charge, but the application seldom is brought through. In other cases, the nurse and/or doctor can donate money so the patient can get food during his stay at hospital. This is done out of charity and pity for the patient. At one hospital I could see a poster to rich people to donate money so that poor people could get the care they need. Below is a quotation showing the culture care descriptors concerning economical matters influencing the nurse's daily job.

*If a patient who has no money is brought to the emergency, **limited treatment is given to the patient and the hospital may pay the bill.** But it seldom happens. **The nurse and the doctor might buy food for a poor patient, without the patient knowing who has paid.** The patient usually writes a note to the hospital and praises the nurses. The doctor and the nurse pay the food with private money. (Nurse.)*

The patient's economical situation creates a will among nurses to help someone who is poor. A professional care practice, in this kind of situation, is to al-

leviate suffering by personal donations, by influencing the medical care given (to the extent a nurse possibly can) and by asking the hospital to pay the hospital bill for the patient who has no economical resources to get the care needed. The nurses have to inform the patient about the hospitalization costs, and if the patient does not have money enough to pay for the treatment, he/she will not get more treatment. This is a difficult situation for the nurse; the patient might get angry and blame the nurse for not helping him/her, and the nurse knows that discounting the medical treatment might be hazardous for the patient's recovery and health. This is especially difficult with child patients.

**Letting the patient's suffering be a family matter is a professional care practice.**

Suffering, especially emotional suffering is seen as weakness; to lose control. This is not appreciated among the informants. Emotional suffering is for the family, not for the public (consisting of strangers, such as the nurse). To show suffering, no matter if it is caused by physical pain, disharmony or by social circumstances is to show weakness and the patient has to show his braveness in difficult situations, and "not lose face". Weakness can be interpreted as disharmony, and bravery is desirable. Below is a statement from a nurse, describing how the patient should deal with suffering and difficult situations.

*Firstly the patient must be people with strong will. No matter what unfortunate things happen even though he or she will be dispirited for a time he or she will face to be bravely at last. (Nurse.)*

A professional care practice to support the family is to support the patient's bravery, and bravery is to keep control and manage to fight a disease. The information about a disease that might lead to death is not told to the patients before they are ready for the news. The patients are ready for the news when they have understood the diagnosis and the situation. The patient has then already found his/her own strategies for how to deal with the situation. This avoids scenes of public emotional suffering and helps the patient to keep the feelings inside and through this also keep his "face". The patient can through pessimistic language show his disharmony and this gives the nurses a sign of suffering, but the patients usually want the relatives around to act on their behalf. The nurse is consequently not the first to comfort a patient. The nurses aim at imparting strength to the patients and aim to compensate for the disharmony of a difficult disease. The methods used for this are not evident to a stranger. When I asked how the nurses can support the patient's strength, I usually got answers describing the nurse's attitude; it is the nurse's positive attitude that strengthens the family and the patient.



There is a fine line between life and death, and this is a part of daily life at a hospital. How do nurses deal with this? This is an interesting question since I already know that emotional matters are mainly discussed in the family and the nurse's support consists of pain assessment and medication, information and education. The nurse's attitude is as mentioned also important for patients and relatives.

The patient's existential suffering is mainly discussed in the light of death. Death is not easy to talk about since it frightens nurses, patients and relatives and is seen as a private family matter. The nurses, when discussing existential suffering and death, connect death to beliefs about what will happen with the person after death. To believe that death is not the final end, (like the Christian belief that life continues after death) make it easier to think about death. According to nurses participating in the study, the patients generally have no religious belief. With that comment they link "belief" to big religions in the Western world like Christianity (Protestantism, Catholicism). However, on a visit to the Buddhist temple in Fuzhou, the capital city in Fujian province, a huge amount of people are there. The nurses commonly do not talk about death or existential suffering with patients or relatives. Below is a quotation showing the informant's perception of the patient's religious beliefs and the influence the faith has on a dying person. The cultural descriptors concerning death and religion are written in bold letters.

*The patients usually have no religious belief, they have grown up under the leader Mao Tse Dung and they are Marxists. The patients believe that death is the final point in life and there is nothing left after that. It is different for you [being a Christian], because after death you can go to heaven to God and life continues in heaven. Maybe Chinese people cannot believe that, after the patient is dead nobody knows what happens. **When you die you are doing something you don't know.** What is happening next? You don't know about dying and you are afraid of dying and death...you [who are Christian] know you believe that dying is to pass away to another life, there are occasions where people say, I was dead before, maybe you have the wrong idea, you don't know what to expect after death and it is scaring. (Nurse.)*

The quotation shows society's influence on people's minds and souls. The informants tell me that under the era of Mao Tse Dung (an era still fresh in people's memory and still influencing the patient's life), no religion was allowed, and it is still not accepted to belong to religious societies. The nurses, patient and relatives agree that it is better to die at home, since it makes the death

a family matter, like it should be. To die in hospital is not as peaceful. When discussing religious beliefs a nurse said that it must be much easier for nurses in Finland to discuss death with patients since we know that there is a life after death. The Chinese patients do not know it, and cannot believe in it; to them death is the final phase of life.

A severe disease is connected to existential suffering and according to the patients it is not good to get to know about a severe disease, and the nurses agree. When the nurses were asked how they would like to be informed if they would have a serious disease, they put themselves in a patient's position and answered that they would also prefer not to be informed about a serious disease. Not being informed is accepted by patients, relatives, doctors and nurses. The following short quotation is from a discussion held with nurses in a focus group. The topic was information to patients and a nurse formulated her opinion as follows

*The best is if I don't know if I have cancer. (Nurse.)*

When a patient is old and suffers from a disease, the nurses see a peaceful death as a goal, but I did not get the impression that ethical discussions regarding resuscitation were commonly held, rather the opposite. Money and relatives decide the care; also when death is approaching. Below is a quotation from a nurse about the procedures regarding relatives wish to keep a sick family member alive and the nurse's view of resuscitation as prolonging suffering.

*The money rules, if you have money you also have value. An old man can be resuscitated twice to a life in pain and unconsciousness but **the relatives want the old man to be alive** and then the doctors and nurses continues with a care that is doing nothing but **prolonging an old mans suffering and life.** (Nurse.)*

The nurse does not influence the situation, and does not take part in the discussion regarding prolonging life or letting the patient die. The nurse sees this as a matter discussed within the family and with the doctors. In the above described situation I could also observe that the nurses did not discuss with the relatives after resuscitation, the relatives supported each other. I could see the daughter crying and the husband comforting her, but the nurses' actions were directed towards the resuscitation and afterwards towards cleaning up. The doctor discussed with the relatives, but the discussion did not include any evaluation of the value of life for an old man, when resuscitated to a life of suffering. This is according to the nurse a family matter and the relatives decide to what extent the old man should get treatment.

At a Hemipurification ward at one of the hospitals the head nurse said, regarding existential matters that are present in the daily life at the ward that death is always present and the worst thing is to lose a young person. The nurses grieve as well as the relatives, but it is not discussed; not even with each other. The nurse's relationship to the patient is, according to the head nurse, supportive. When visiting the ward it can be seen in the nurses' way of talking and acting; they act like they know the patient very well, although the nurses do not talk about the most obvious thing with the patient, the fact that their disease, according to the nurse, will lead to death sooner or later. The nurses have a kind approach to the patients and always have a smile on their lips.

**Encouraging hope and seeing it as an antidote for suffering is a professional care practice.**

When asking the nurses to discuss the most important situations, tasks and goals with nursing, the nurses rank making the patient happy and secure as the most important. This is done in co-operation with the relatives. To make the patient happy is to not let him or her be worried. The second most important goal is to relieve pain. Pain is seen as a physical sensation and painkillers are used to remove pain. When talking about suffering, the nurses commonly include psychological pain and suffering due to lack of money. The third most important task is to keep the patient both physically and mentally healthy. The nurses mention that they have to keep the patient in a positive mood and instill hope in the patient. This will help the patient to be cured or to live with a disability. To keep the patient in positive is to help the patient maintain hope for recovery. Below is a quotation where the professional care practices aiming at helping the patient to live a happy life are in bold letters.

***I don't think it is a good thing to tell old people about a serious disease, to accept this at the end of life...maybe we just need to help the patient to live a happy life.** (Nurse.)*

To help the patient to live in the present, and to not force the patient to learn all about a severe disease is seen as a way of helping the patient to remain in harmony. Not having to face a difficult situation can be seen as a way of helping the patient live in the present. Nurses have to support the patients in order not to let them down. Not talking about or showing the patient the severity of a disease can be seen as protecting the patient. It is a protection from losing hope, from having to change from the person the patient is used to be into somebody else.

To be happy and in harmony is important to the patient. To cause disharmony

and sadness is to cause harm to the patient. The patient is cared for in a special way when ill, and this is because the nurses want to indirectly prepare the patient for a hard time by helping him or her to be brave and maintain control. If the patient gets suspicious, the nurse might cause him emotional suffering and raise questions that have no answer. A nurse explains it as follows:

***We will talk to the patient indirectly. In the beginning we need to give medicine and relieve pain but not too obviously, you may not make the patient suspicious. You just act like to a normal patient. In the beginning you may not show too much concern for the seriously ill patient, because then he will come and see you and talk to you every half an hour. When the patient gets ready to know all the news we will tell them but after knowing they are showing emotions and we will show more concern. (Nurse.)***

The nurse shows her concern by non-verbal communication and signs which are not always visible to a foreigner. To alleviate pain is by the nurses seen as a good way to maintain the patient's hope for recovery, since pain is a sign of disease and the absence of pain gives hope. The nurse shows more concern and, as I could see it, the concern is shown in the nurse's attitude, the smile, and small talk with the patient. The professional care practice aiming at transferring hope to the patient is to show concern and to promote harmony.

## **Visualization of practices, values and beliefs among nurses at hospitals in a Chinese setting**

In this chapter the above described themes and patterns are visualized. They are briefly described and refer back to the previous description of Chinese culture and previous research concerning suffering and caring.

What do Chinese nurses do when they alleviate suffering and what is the meaning of their actions? Can the Chinese nurses' ways of acting be understood in the light of Western nursing research concerning suffering and caring? One the one hand no, and on the other hand yes. By connecting the findings reported above to Western nursing research results, the Chinese way of acting can be "translated" and interpreted into a Western understanding, but this is hazardous, since it can also lead to misinterpretation where cultural blindness is an obvious risk. The meaning behind the nurses' actions is founded in the culture. Cultural knowledge is consequently needed to fully grasp it. The Western nursing research can help to understand general tenets in the nurse's job, and by connecting the new insights to these, one can gain new understanding.

Below is the visualization of the nurse's voice and professional nursing care regarding caring and suffering among patients and their families at hospitals in Fujian province. In figure 4 the professional care practices follow the patterns described in the presentation. The beliefs, seen to the right of the figure underpin the values seen in the middle of the figure. The connection is visualized in an arrow pointing from beliefs to values. The arrow from values to professional care practices show that the values in the culture influence on the care practices. The themes are differently named in the presentation than the values in the picture and this is further explained below. The beliefs are formed by the patterns and the themes, and are the conclusions of the values and professional care practices. Firstly a visualization of the practices, values and beliefs is presented and it is followed by a discussion of the nurse's role, professional care practices and the values and beliefs underpinning professional care practices.

### ***The nurse and professional care practices***

The concept nursing in Chinese is "Hu-Li" which means protection and management (Kao et al., 2006) and both protection and management are seen in the presented study. The nurse in a Chinese context is distanced from the patient's emotions but professional in her delivery of nursing care. She has a task-oriented approach, a curing paradigm and highly appreciates medical knowledge and technical nursing skills. This is where the management in the nursing role can be seen. One of the highest ranked nursing tasks among the informants is to keep the patient healthy both physically and mentally which fits into the nurses' curing paradigm.

Chinese nurses have a family-centred approach in their job and the care is family and patient lead although the nurse remains distant to this influence in decisions regarding the patient's care. It is natural in a Chinese context to work with the family since the patient is seen as a part of the family entity. The nurses do however find the relatives as obstacle for the nursing care and find them demanding in their requests, a finding compatible with Pang (1998b).

The Chinese way of viewing a person is to put the person in a social context and the person is viewed based on her role and position in the family (Jakobsson, 2001; Kao et al., 2006) and this gives the family-centred approach significance. The family-centred approach is also discussed by Leininger (1991, 1997a, 2002b, 2005a) who emphasized that a patient should not be seen as isolated, and the whole family should be seen as care recipients and caregivers. Commonly the sufferer is seen as the patient, but people involved in a patient's life suffer as well, which is described by Tapp (2001) and Smith (1998). The

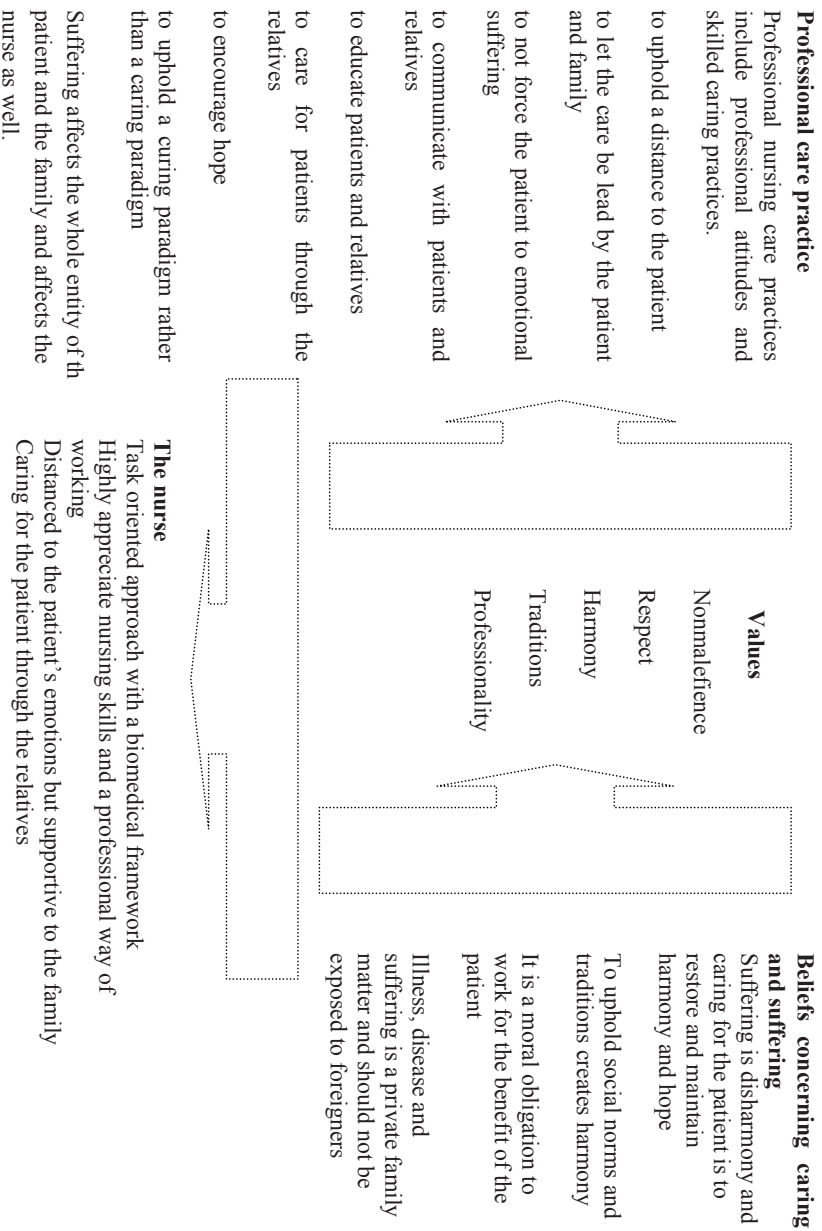


Figure 5. Visualization of nurse's professional care practices, values and beliefs.

family and those who care for the sufferer are also affected by the suffering. The Chinese nurse sees the family as care recipient and caregiver, and let the care be led by the family. She slips into the background in the basic care but with her professional nursing skills she supports curing. This feature does not make the Chinese nurse insensitive. The nurses suffer with the patients and situations where they cannot influence the outcome of the care (cf. Morse & Carter, 1996). The nurses mention situations where the patient has no money for the care, when suffering is not bearable and when disclosure of a severe disease causes emotional suffering as the most difficult situations. This is congruent with Pang (1998b), who in her research described disclosing information to patients, handling patients' or families' demanding requests, requests for euthanasia, inability to pay hospital fees and mismanagement of patient care as difficult situations for the Chinese nurse. Similar findings can be seen in this study.

In Chinese nursing information and education are methods used to reach the patient through the relatives, and this alleviates suffering. The patient's suffering is mainly shown to the relatives, while the nurse is exposed to the patient's enduring phase (cf. Morse & Carter, 1996). Communication can be seen as a caring relationship where the nurse shows her concern to the family and the patient. To see communication as a caring action, is also described in the Western research publications (Davis, 2001; Fredriksson, 2003; Graber & Mitcham, 2004; Kruijver et al., 2001; Manderson & Allotey, 2003) where communication is described as showing compassion in the relation between nurse and patient. In the nursing model developed by Kao et al (2006) the nurse has to restore the patient's harmony and in the relationship with the patient bring her own harmony as a resource for the patient.

Communication with the patient is important and communication is commonly seen as a learning situation where the patient gets information. The nurse sees it as an obligation to educate and inform the patient and family, in order to help them make correct decisions and help the family care for the sick family member correctly. This is congruent with how Johansson et al. (2002), Hemsley et al. (2001) and Stensland and Malterud (1998) describe communication when aiming at helping the family to take part in the nursing process. It is also congruent with Haigler et al. (2004) who discuss the importance of support for the family as caregiver when the family carry out tasks commonly conducted by professional caregivers. In China it is natural to be a part of the nursing process and in the Western culture nursing research tries to find models for how to involve the family more in the care. This is due to the expanding need for care at home when the patient is suffering from a severe and chronic disease (Kitrun-

grote & Cohen, 2006). Among Chinese nurses communication is seen as a way of caring for the patient and the family which is also described by Kruijver et al. (2001) and Manderson and Allotey (2003). The nurse's communication with patients consists of education, which can be seen as instrumental communication (cf. Kruijver et al., 2001) but also of caring actions where the nurse indirectly and with non-verbal language shows her concern and care for the patient. This communication is by Kruijver et al. (2001) described as affective behaviour through which the nurse let her respect for the patient be shown.

The nurses consider it important to make the patient happy and secure and to relieve pain and suffering. The patient is seen as vulnerable, and suffering should be avoided and even in certain situations, unnoticed with caring actions such as touch, since touch might bring a patient into emotional suffering which is not acceptable in public. This can be seen as protection described by Kao et al (2006) when outlining the meaning of the concept nursing in Chinese. The nurse helps the patient to endure suffering (cf. Morse & Carter, 1996) and not to slip into emotional suffering where the patient loses control. This shows respect and gives dignity to the patient and can be seen as a caring action. This is different from the research reported in Western literature. According to Lohne and Severinsson (2005), Morse (2001) and Starck (1992), hope begins to emerge when a patient has suffered enough. The patient has to "live through" the personal suffering (Eriksson 1994, 2006) to find hope and new direction in life. In the Chinese context suffering is not seen as a way to gain hope, but as destroying hope and the Chinese nurse describes hope as an antidote to suffering. To have harmony, although you are suffering, is the way of "living through" the suffering in a Chinese context and an important professional care practice is to prevent the patient from experiencing suffering.

Illness and suffering are seen as a private family matter and a part of life which is congruent with the findings Mok (2001) and Pang (1998a, 1998b) describe. Mok (2001) found that patients have to accept illness because it is a part of life. The acceptance of illness is enhanced by the traditional Chinese cultural beliefs of harmony with the universe. The nurses mention that they have to keep the patient in a good mood and give hope to the patient. This will help the patient to be cured or help the patient to live with a disability (cf. Chen, 2001). The nurses emphasize keeping the patients in a positive mood and helping the patients to restore and maintain hope and harmony. When working for the benefit of the patient's health and wellbeing, professional skills are needed and the benefit of the patient's health is a common value in nursing which is described by Chen (2001) as the moral obligation to do good for the other.



The nurses are affected by the patient's suffering, and supervision is a way of dealing with the difficult feelings that arise from not being able to cure or ever ease the situation for the patient. To keep a distance to the patient and his or her suffering can be a way of managing difficult situations. The patients' and the relatives' suffering influence the nurses' lives especially if the suffering cannot be relieved. Similar findings are also reported by Barbato (2004) and Rowe (2003). The nurse can experience suffering due to helplessness in the specific situation, but also due to social or other circumstances (cf. Eifried, 1998; Jezuit, 2000, 2001; Maeve, 1998; Morse, 1996b; Smith, 1998; Tapp, 2001; Rowe, 2003 and White et al., 2004). Nurses upholding a distance to the patient and the patient's family can also be a way of protecting the nurse herself from suffering. The nurses also stress the need for supervision in difficult situations which is described by several nursing researchers (Eifrid, 1998; Jezuit, 2000, 2001; White et al., 2004). Rowe (2003) says that isolation maintains suffering in the healer, and in a Chinese context the distance to the patient can be seen as a form of isolation of suffering. According to Rowe, one way of reducing suffering of the healer is to reduce isolation. This could be done by supervision, in which difficult situations are discussed.

### *Values that form the basis of professional care practices*

The values described below are derived from the cultural care descriptors found when analyzing the collected material. The values form the themes that are presented, however, different kinds of values than the previously mentioned can also be seen. The value nonmaleficence, respect and harmony are visible in all themes presented and can be seen as terminal values. The traditions and professionalism are seen as an instrumental values used to achieve nonmaleficence, respect and harmony. The values are marked with italics in the text.

*Harmony* is an important goal for professional nursing care and the nurse strives to support the family and the patient in maintaining or restoring harmony. It is accordingly not appropriate to act in such way that the patient gets upset, worried or sad. This creates disharmony, not only for the patient but also for those surrounding him. Harmony should be the goal and when the patient is in harmony he or she can handle bad news and difficult treatment. Harmony also includes hope. These features can be recognized also in Western nursing research, concerning the nurse's way of being with the patient. Halldórsdóttir (1996) in her research describes different frameworks for the nurse and for her interaction with the patient. The nurse's way of being with the patient can, according to her, either support or destroy life. The Chinese nurses discuss the

way of being with the patient in the light of a moral obligation to do good for others, which includes a professional approach to the daily work. The level of professional skill and the appreciation of it are dependent on several cultural dimensions such as technical, educational, social and political structure dimensions. Professional skills in nursing mirror the educational level in nursing as well as its social and political status in the society.

Moral values like *respect* and *nonmaleficence* have to be present in professional nursing care, and one example of these is the Chinese nurse's choice to let the care be led by the patient and his/her family. The nurse follows the families' and the patients' decisions regarding for example truth-telling. This can be understood in the light of Saeteren's study (2006) in which she describes suffering among patients in palliative care. She claims that suffering can occur when the care is not based on respect and sensitivity to the patient's existential situation. The nurse lets the family take the lead, and she bases her actions on the families' and the patients' expectations of care. The following moral values are also recognizable in the Western view of the encounter between professional knowledge and the nurse's moral values, which form clinical nursing as it is viewed by Nortvedt (2001). Sensitivity to the vulnerable patient, who needs to get support in order to maintain or restore harmony and hope, creates clinical knowledge and is culturally bound. The reaction to and ability to understand another person's suffering is an ethical and cultural act and it varies depending on cultural belonging (cf. Jones, 2003).

### ***Beliefs underpinning professional care practices***

When summarizing practices, values and beliefs influencing the nurses' daily life, one can conclude that the patient is in focus. The beliefs represent the "thick description" and answer the question what the meaning behind certain actions is. Each belief is formed by comparisons within cases, listening to the voices of several informants and observing several events. The patient seeks help for health problems and the nurse and other medical staff are there to help the patient. The ultimate goal is to cure the patient, and a curing paradigm is evident at hospital. This is expected, since the family cares for the patient and is responsible for all care that does not involve medical knowledge. The relatives are expected to monitor the medical care and help the patient to get treatment. This is a foundation of a curing paradigm and work influenced by the biomedical model. The statements headed as beliefs are derived from the themes, the patterns and culture care descriptors found through analysis. The beliefs are seen in the nurses. They are founded on the values that penetrate the life of the group in question at the hospital. The beliefs are written in italics.

The first statement or belief is *“Suffering is disharmony and caring for the patient is to restore and maintain harmony and hope”*. The value of harmony has its roots in Chinese philosophies and it is important to uphold harmony, since individual disharmony influences the society or the group. One of the important duties in nursing is to help the patient to maintain harmony. To avoid emotional suffering, conflicts and to act professionally are methods for maintaining harmony. The nurse can also through her own harmony try to change a patient’s disharmony, which is also described by Kao et al. (2006) when describing a nursing theory specific for Chinese nursing. Kao et al. (2006) present a holistic view of a Chinese nursing metaparadigm, constructed by reflections on Chinese philosophies and Rodger’s theory of unitary human beings. Harmony is an important part of Chinese values embedded in Chinese philosophies and this is seen as an important concept in the model. Kao et al. (2006) emphasize the importance of the nurses’ own harmony in order to be able to change the harmony status of the patient. Harmony, equilibrium is seen as health and disequilibrium, disharmony and illness belong together. Nursing is characterized as recovering harmony or compensating disharmony. During the period of harmony, nursing intentionally promotes harmony and during times of disharmony the nurse’s task is to compensate the disharmony with harmony. The model uses concepts and ideas from both traditional Chinese philosophical values as well as Western ideas of nursing. To restore and maintain hope is part of the concept of harmony. There is no hope if disharmony is present; hope can only be developed when the patient is spared from worries. The second belief is *“To uphold social norms and traditions creates harmony”* and is linked to the first belief. It is important for the nurses to uphold the social norms; it creates stability in the society. The nurse allows patients to have relatives at the ward day and night. Several visitors are allowed and the nurses educate the relatives so they can care for the sick family member in a safe way. The hospital is a place where the relatives care for their sick family member under the guidance of professional nurses. This practice is congruent with the family-centered model suggested by Dunst et al. (2002). The model emphasizes the family as capable of caring for their own family members. In the Chinese context the nurse works through the relatives for the benefit of the health of the sick family member and also supports the family as being the resource for caring for the patient.

The third belief is *“It is a moral obligation to work for the benefit of the patient”*. The professional skills mentioned by informants mainly concern technical skills and education. The informants mention curing as the main goal of their actions. Showing compassion in nursing care is discussed as a

professional act, and the compassion is shown non-verbally with signs and symbols, even though it is not the highest ranked value in professional nursing. The nurse is not close to the patient and the compassionate nurse is less appreciated than the technically skilled nurse. The nurses manifest a curing paradigm with emphasis on actions directed to curing or the alleviation of pain. Technical and educational developments are important in nursing and medical treatment is highly appreciated. Although the nurses have a curing paradigm there is a deep motivation for doing good to the other present. There is also responsibility for life; both your own life and that of others (cf. Edlund, 1995, 2002).

The last belief is *“Illness, disease and suffering are private family matters and should not be exposed to strangers”*. The statement has its basis in the Chinese values regarding family, harmony and the control of feelings. The economical situation probably also influences this belief; the family has to make decisions based on their economical situation. The belief brings a dimension to nursing where the nurse influences the care through relatives, and does not intrude by taking on the role of primary care recipient.

### **The social structure’s influence on suffering and caring in a Chinese setting**

The social structure of society influences caring and this chapter will briefly give a description of different factors which influence the patients’, relatives’ and nurses’ suffering when linked to the structure of society. Care and caring are also influenced by the social structure. The concept “social structure” includes economy, religion, health care, education, family and the values which underpin the development of cultural expression in a Chinese context. The chapter can be seen as a summary of how the social structure influences the patients’, families’ and nurses’ daily lives.

Suffering due to social circumstances is defined by the informants as being caused by not being able to afford treatments and by being abandoned. Kleinman, Das and Lock (1997) describe social suffering as resulting from political, economic and institutional power. To whom can a poor patient complain and show his or her suffering in the hope of being cared for? If the family and the extended family cannot help the patient, he/she is helpless. Charmaz (1999) and Cope (2000) in their studies highlight how the suffering of someone with low moral status may be ignored or minimized. This can be seen in China, and it forms a class system where some people’s lives are more valuable than others. This unmentionable class-system is displayed when the individuals who

do not have the economical resources to buy the care they need are left uncared for. Financial issues influence the patient, the families and the nurses.

Economy forces the Chinese system with family centered care into new directions, due to the one child policy. The tradition of having a relative at the bedside during hospitalization is not possible for all families today since the families are not big enough. There are no sisters or brothers to share the responsibility for a sick family member (cf. Zhan, 2005; Wong & Pang, 2000). The tradition of having somebody bedside can continue by hiring a relative, a Hu Gong. The Hu Gongs have low status since they have no education they act instead of a relative but have no influential power as a relative does. The Hu Gong has no working hours; he or she is on duty according to working schedule and can be tied to the patient 24 hours a day. The agreement is naturally based on mutual understanding, and the employer has to take care of the Hu Gong as well. However when listening to patients and relatives stories about Hu Gongs' working conditions, they do not sound reasonable in a modern country.

Taking care of sick family members is mainly the daughter's or the female family member's task. One of the informants in this present study verbalized this task as "*it is only one who has to give up the job*". This can be seen as a burden but also an opportunity. Hogstel et al. (2005/2006) finds that the burdens and strains of family caregiving for the elderly are frequently reported in health-related literature, while the benefits are often ignored but Zhan (2005) describes the situation in China as a gender situation and women have usually been the care providers for parents. Women can get income for giving care by being paid by the siblings.

Health care is developing rapidly in China now which can be seen in the Chinese government's concentration on rural areas. Due to a more open policy the Chinese health care system can benefit from influences from all over the world. The doctors get their education abroad, the nurses work abroad and Western companies find that China is the land of possibilities. This creates a ground for rapid medical and organisational development. The one-child-policy influences health care in other ways than the lack of relatives to care for the sick family member; the nurses can have a professional career, only having one child to care for, and commonly the young family gets help from grandparents in caring for the child. The population decreases and the young people who want to study do not choose nursing as the first alternative due to low status and low income. This is visible in the lack of nurses at the hospitals. Many of the young nurses I met come from the rural areas and they are the first generation in their family

who has had possibilities to study and get an education. The education in nursing is developing and today nursing can be studied on Bachelor's, Master's and even Doctoral level at some universities. The development of nursing models are based on Chinese culture is developing (cf. Kao et al., 2006), which will probably change nursing profession in the future. The Western nursing models cannot fit into Chinese society, since they are constructed in another culture, with other values which influence activities concerning caring for the suffering patient. The Chinese nurses' ways of working with patients is not built upon the same foundations. Promotion and prevention are natural parts of TCM, and also important parts of the nurse's education of patients and relatives. However differences in paradigm between the nurses and the suffering patient, can, in some cases, cause more suffering than the disease itself. (cf. Arman et al., 2002; Arman et al., 2004). This can be seen in situations when the patient and the family do not trust the treatment and do not follow instructions.

Health care in China is built on private and company insurances. There is no governmental support for people who lack the money for their care. The hospitals have to raise money to uphold the activity and the patients have to pay for their care. The doctors get provision for the medications they use and this creates a situation where the patient and the family feel that they need to control the doctor and his or her prescriptions<sup>51</sup>. The relation between the patient, the doctor and the hospital must therefore be built on a sound ground. This creates cases of doctors and nurses who are aware of the patient having to pay for care, and the care cannot be too expensive, but the fees must cover the costs and leave some money for development of the hospital. Although the patients know, since it is a cultural pattern, that the family will take over the responsibility for decisions regarding truth telling and regarding treatment, the patient trusts the doctor's decisions and suggestions for treatment. They see these as one of the fundamental factors in caring for patients. The economical situation is one reason for upholding the tradition of having a family member at the bedside and bringing food for the patient. All costs that can be cut down benefit the family, but economical reasons are not the main reason for the relatives to stay at the hospital.

The economical situation creates a dilemma for the family, especially if the person in need of care does not have the possibility to get the necessary treatments. This creates a system where money decides the value of a person's

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<sup>51</sup> According to the Chinese Health Minister Gao Qian (Desheng in China Daily 05.08. 2005) the health care system today in PRC allows overcharging of the patients. The doctors can prescribe expensive medications and unnecessary health follow ups because of personal benefit in the form of provision.

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health and life. The suffering that emerges from a patient's bad economical situation also befalls the nurses. The nurse is commonly the person who has to tell the patient that there will be no further treatment and then has to face the patient's anger founded in shame.

There are several religions in China, which work side by side with several philosophies of life. The outlook on life influences on the care given. The Chinese culture is founded in Taoism, Confucianism, and Buddhism mixed with Atheism and Marxism. There is not one single dominant outlook of life, but a general outlook of life that is visible in daily life. It is seen for example in the longing for harmony and the avoidance of disharmony and conflicts. Another feature is upholding a façade, not showing feelings and not losing face and finally the private and family-centred way of handling matters, not interfering if not invited.

The social suffering described by Kleinman and Kleinman (1997) can be interpreted as a part of cultural pain (cf. Leininger, 2002a, 1997b). Culture and cultural pain have their roots in the social context of the person who is suffering. Gender, class and ethnicity may play a role in shaping the suffering experience. The nurses in the study claim that women can stand pain better than men and that people from the rural areas have a higher pain-threshold than people from the urban areas. This tendency to put patients in boxes depending on social belonging is probably not exclusive to China; similar ways of grouping patients can probably be found all over the world. It is nevertheless a violation of dignity of the patients, who probably do not have anyone to act as their advocate and give them a voice (cf. Charmaz, 1999; Cope, 2000).

## CONCLUSIONS

### 11. Suffering and caring

This study focuses on the cultural care practices, values and beliefs that underpin the interpretation and understanding of suffering and caring. Care and caring conducted by family and professional caregivers have cultural and symbolic meanings and are essential parts of the culture (cf. Leininger, 2005a). Suffering is a universal experience but expressions, expectation of alleviation and caring practices related to suffering are embedded in a given culture and consequently differ culturally. In the following chapter the empirical findings will be discussed in the light of the theoretical perspective and previous research. The study does not intend to compare two cultures regarding experience and expression of suffering and the delivery of care. Nonetheless, the discussion concerning the findings in this study will benefit from both theoretical perspective and previous research when concluding the findings. The study can build bridges where findings in one culture can nourish theoretical development in another culture.

#### **Conclusions based on the empirical part of the study**

When the results from the empirical study are related to the theoretical perspective and earlier research, patterns of interpretations are related to each other open up an understanding for how suffering and caring is experienced, expressed, interpreted and understood among patients, relatives, nurses and Hu Gongs. The conclusions based on the empirical part of the present study are listed below.

1. Suffering and its manifestation are intrinsically linked to the worldview, and the culture forms a framework for actions and reactions related to suffering in a Chinese context.
2. Suffering is described as a private and family matter in Chinese society, where the professional caregivers are not directly involved, unless invited.
3. The dissolution of the drama of suffering might be harmony and resolution or disharmony and anxiety. Harmony and resolution are supported by caregivers in a Chinese context.



4. Caring for the patient is mainly a family responsibility in the Chinese contexts, and the professional caregiver cares for the patient with and through the family.
5. The family as caregiver is a strong tradition in a Chinese society. Caring is embedded in the culture, which forms a framework for the current caring actions.
6. Care delivered by professional nurses in a Chinese context presupposes the ability to correctly interpret and understand messages of the patient's and the relative's (family's) need for care, and correctly administer nursing care.
7. Good professional skills are emphasized in nursing care in Chinese contexts.

Suffering is a universal experience shared by all human beings, it is a part of life and it cannot be fled from; it has to be accepted. Cultural and social structure dimensions form the experience, expression, interpretation and understanding of suffering. A study like this cannot claim to offer a full description of suffering and caring in China, but it describes one Chinese context. The results can be seen as keys, opening up for a discussion about how suffering is experienced, expressed, interpreted and understood. The keys are the generic and professional caregivers', descriptions of suffering, the drama of suffering, and the cultural patterns influencing care and caring for the suffering human being.

### **The family and the professional nurse as caregivers**

Culture and care are both independent and linked together. To correctly administer care, the carer needs to be familiar with the culture and correctly interpret the patient's need for care (cf. Leininger, 1991, 2005a). Caring is seen both in generic and professional settings, and professional care carries elements of generic care in its practices (cf. Eriksson, 1987). The compassionate carer is somebody who cares with love. In a Chinese setting this is the relatives in the family (or the hired family - Hu Gongs). Care and caring are not only the professional's task and mission the family is equally important (cf. Leininger, 2005a). This is clearly seen in the Chinese context. Caring for a sick family member is also a symbolic act, the sick person is not abandoned, and the relative is given a symbolic function when the Hu Gong enters the scene. The Hu Gong has tasks to do, but should also be seen as a daughter and behave like a daughter since it is the daughter of the family who should care for the sick relative (cf. Zhan 2005). The family caregivers have a caring paradigm, where

the main issue is to keep the sick family member connected to the family, protected from worries, assured good care and helped to achieve harmony. The family, relatives and Hu Gongs have a natural part in caring for the patient.

Eriksson (2001) sees the caring relationship as forming the meaningful context of caring and derives its origin from the ethos of love, responsibility and sacrifice, i.e. a caritative ethic. The caring relationship is described in the assumptions underpinning the theory of caritative caring and it emphasizes that caring is formed in the relationship between the patient and the caregiver (Eriksson 2001). Although “the caregiver” can include the family, the present study further necessitates that the family as caregiver is supported by the professional caregiver (cf. Wiles, 2003; Lopez 2007). This can change the role of the family to a recipient of care. The role of the family as caregiver and care recipient needs further discussion, not only in a Chinese context, but in other caring contexts, in form of involving the family in the caring relationship. The caring relationship carries the desire to alleviate suffering for the sufferer, which implies responsibility and sacrificing for the benefit of the sufferer (cf. Eriksson, 2001). In a Chinese context the caring relationship is mainly held within the family, and elements close to the description of the caring relationship are visible (responsibility for the other and sacrifice for the benefit of the other are values that underpin the Chinese culture) (cf. Hsiao et al., 2005; Jakobsson, 2001; Kao et al., 2006). The family can therefore be seen as an important part of the caring relationship.

Care and caring have cultural and symbolic meanings and are essential parts of the culture (cf. Leininger, 2002b, 2005a). The way caring is delivered is bound to the cultural values that underpin the actions. The general idea of caring is universal and caring is what makes people human (cf. Leininger, 1991, 1995, 2002b, 2005a). The relationship to close relatives is important, which is shown in the present study. The person in a Chinese context is related to the position in the family (cf. Jakobsson, 2001) and a person is seldom viewed as an individual. The family has an important part in both caring and curing.

Caring in China is interpersonal and it exists in the relationship between the patient and the family. Caring also exists in the contact between patients and nurses, but the caring acts are often done through the family (cf. Heigler, 2004). The sick family member is set aside – but with love. The nurse’s caring is an extended act. The Chinese family takes over and carries the worries as far as possible. This is congruent with Chinese values where interpersonal relations are important (cf. Hanssen, 1998; Wang & Pang, 2000; Pang et al., 2000)

and a person is described through his or her social role (cf. Jakobsson, 2001). The family acts as primary caregivers' and the nurse does not take over the responsibility for caring from a close relative in the family, the care is family and patient led. The nurse's role is supportive, she gives out information and educates the relatives and the patients, and these methods are the nurse's way of reaching the patient and the family and guarantee good care. Through a positive attitude she brings harmony to the patient.

In China the hospital can be seen as a place where the family cares for their sick family members under the guidance of professional nurses. This moves the nurse's focus from being a support for the patient to being a support to the family. The nurse's professional skills are important, and her ability to function as a compassionate carer slips into the background. This does not mean that Chinese nurses act without compassion. They do care for their patients, but put emphasis on technical and educational skills, and use these as a method for the benefit of the patient's curing and health. The professional care carries elements of generic care in the form of shared values and beliefs (Leininger, 2002b, 2005a). In order to fully understand the professional care, the cultural values underpinning the care need to be clear. It is impossible to correctly interpret the silent requests from the patient and relatives for care and cure without understanding the cultural values.

Culturally congruent care is dependent on cultural competence. Caring can only take place when care values are brought to the surface, and caring is delivered in an appropriate, safe and meaningful way (Leininger 1991, 2005a). The worldview influences both generic and professional care, which are delivered individually by nursing staff, relatives and institutions.

Based on the present study, there is a necessity to further investigate the family's role in caring for the suffering human being, and relate it to the theory of caritative caring. To include family caregivers in the description of the caring relationship also need to be discussed. It is also necessary to let the professional care focus on the family as a resource and support the family as caregiver and care recipient. The following assumption is derived from the present study and it is a suggestion for a further development in broadening the assumptions concerning caring in the theory of caritative caring.

*The family (relatives) are natural caregivers and also care recipients who need to be seen by the professionals. They also need support in their caring for the sufferer by professionals, and to become a natural part in the caring relationship.*

## Suffering, caring and culture

Suffering according to Eriksson (1994, 2006) is divided into three different forms of suffering namely existential suffering, suffering caused by a disease and its treatment and suffering caused by non-caring actions. Suffering in a Chinese context is linked to disharmony. It is described by patients, nurses and relatives as *physical* (then linked to disease, accident or disability), as *psychological* or mental (then linked to behaviour where the patient cannot control him or herself), as *existential* (linked to death and issues in relation to religious beliefs) and suffering due to social circumstances, "*social suffering*", (linked to loneliness, economy - such as lack of money and work e.g. unemployment). Suffering caused by social circumstances is by the Chinese nurses described as worse than suffering due to physical and mental illness and treatment.

Generic and professional care aims at relieving suffering. Suffering due to illness and treatment is in a Chinese setting commonly linked to physical pain. Pain can be relieved by painkillers, and by comfort (of course there are situations where painkillers have no effect and the suffering is getting unbearable, and pain relief seems unattainable. These situations cause a threat to life).

Suffering due to mental reasons is in a Chinese setting linked to control and to achieving or maintaining harmony which is one of the important goals for the professional Chinese nurse. In a Chinese setting, suffering is mainly private, and it is not shared, since sharing does not automatically ease the burden; to share suffering can be to spread the burden (disharmony). To suffer in silence, hidden from outsiders, is a way not to spread disharmony and to show bravery. The suffering is private and a stranger is seldom invited to act as a co-sufferer and to share the suffering, not even if the suffering is caused by illness or treatment. An invitation from a stranger, like the nurse, to share the patients suffering, can then be an act that causes cultural pain. Suffering demands bravery from the sufferer, according to the informants participating in the study, which is congruent to Eriksson (1994, 2006) who says that to truly live is to dare to suffer. To suffer can involve the choice of how we want to live our lives.

Suffering due to non-caring acts, caused by professionals or generic carers is mentioned in the Chinese context. The suffering described is caused by neglecting patients. The expression of this form of suffering is complicated, since it is not appropriate to openly criticize and create conflicts; the generic carers act as advocates and voices for the sufferers.

One way of understanding suffering caused by social circumstances is to con-

sider it as a threat against life itself, as an existential suffering. The understanding of suffering due to social circumstances as existential suffering leans on the informant's expression of this form of suffering as worse than other forms of suffering. It is worse since it cannot be relieved by others, and the suffering causes a sense of helplessness for the observers as well as for those involved. Suffering caused by social circumstances results in feelings of shame, guilt, loss of value and loss of dignity, as explained by informants in the present study. Another way of understanding the suffering caused by social circumstances is to describe it as a form of suffering of its own, not linked to existential suffering. The suffering has political and economical reasons for its occurrence and is then caused by other people, social systems, institutions, norms and laws. This way of viewing suffering brings a social aspect to the descriptions of the different faces of suffering. There are tenets which cross cultural borders concerning how suffering is experienced, expressed and understood, but the manifestation of suffering is seen in the individual experience and is enclosed in cultural patterns of how it is expressed, interpreted, understood and relieved. This manifestation is founded in the values that underpin the worldview of a culture.

The present study shows the importance of taking culture into consideration when caring for the suffering human being. The culture of a people forms the framework within which the experiences and expressions of suffering and care actions take shape. The cultural values that underpin the actions vary within a culture and cross-culturally. Culturally competent care can prevent increased suffering and promote health. The importance of considering culture in caring necessitates a broadening of the assumptions that underpin the theory of caritative care. It is necessary to include culture in the picture of the caring reality, and through this also include culture in the ontology and epistemology of caring science.

*Human beings shape a culture, and care and caring values, beliefs and practices are embedded in the culture. Consequently there is a need to consider cultural values, meanings and beliefs in caring for the suffering human being.*

## **The drama of suffering**

To live is to suffer and suffering is private and a sufferer is always, to some extent, alone in the suffering, and has to go through his or her own drama of suffering. The phases of the drama of suffering are culturally bounded to the manifestations of phases in the culture. Eriksson (1994, 2006) and Wiklund (2000) describe suffering as a drama which the sufferer lives through. Differ-

ent phases of suffering can be detected; the confirmation of suffering presupposes the suffering itself, and the progression in a final reconciliation which is a way of reaching a new wholeness. The sufferer has to work through the phases and adapt to a new situation. According to Georges (2002), the Western view of suffering has its roots in the suffering of Christ, which gave suffering a meaning. This is not necessarily the fact in other cultures. Suffering is by Eriksson (1993) seen as evil and unnecessary, a viewpoint shared by the informants participating in the study.

The informants in this study discussed suffering in slightly different ways. Suffering is to be avoided, and when the person is ill, he or she needs to be cared for by loving and caring close relatives who carry the suffering until it is bearable for the sufferer. This is in congruence with Eriksson (1993, 1994, 2006). The confirmation of suffering is not a visible phase in the Chinese context, and it is not discussed. The informants in the present study describe an unobtrusive patient (who is suffering) who is unconscious of his or her own situation, and this gives no possibility for an outsider to confirm the suffering and to support a process of “working through” suffering. The drama of suffering does however exist in the Chinese context, but with different roles and different meanings. The Chinese patient exists within the role that he or she has in the family. The Chinese culture emphasizes a family-led care, and this brings forward the importance of ascribing a space to the family in the drama of suffering (cf. Bondas, 2000; Dunst, 2002). Leininger (2005a) emphasizes that people exist in relation to each other and the social perspective is visible in her theory. This supports the idea of giving the family a role in the drama of suffering and acknowledging the importance of the family as a support for the sufferer.

The informants emphasized harmony in all stages of suffering, and harmony is both individual and shared. Harmony and hope are to be upheld and this is done by protecting the sufferer from knowledge and thoughts about the illness. To think of illness decreases harmony and increases suffering. The confirmation of suffering is done based on the sufferers own maturity regarding readiness to face suffering. “White lies” which aim at protecting the sufferer from insight into his or her own situation are accepted by all counterparts in the drama of suffering, from a Chinese perspective. The suffering itself is not shown to people outside the family, unless they are invited to share the situation. Suffering is from a Nordic perspective to be shared with a co-sufferer and it is important to work through the suffering, in order to find relief and reconciliation (Eriksson, 2006; Fredriksson, 2003; Wiklund, 2000). To endure suffering is a way of sustaining hope. To endure is also to be in the “midst of” suffering, not having

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a clear direction for where to go (cf. Morse, 2001). Enduring is one phase of the drama of suffering in a Chinese setting and it is supported as a necessary phase.

The nurses and doctors in a Chinese context avoid sharing the suffering. Control is encouraged, since control presupposes harmony. Harmony and reconciliation are similar outcomes, both aiming at helping the patient to live a satisfactory life. The model of the different modes of suffering created by Eriksson (2006) does not facilitate the understanding of the “social suffering” (which has a political, economical and also a cultural foundation). The social suffering, as it is expressed in the present study, is not open, but surrounded by shame, and economy is a family matter only dealt with in the family. A model built upon Chinese values and beliefs is needed to understand the patient in this context and it facilitates acting in accordance with alleviating the social suffering.

Suffering due to social circumstances can, among other situations, be seen in the economical situation that hospitalisation creates for the family. This is a vital question since it decides if the patient gets care or not and is linked to the existence of life itself, but also to the value that a life has in a culture. The drama of suffering differs depending on social structure and is enclosed in the cultural patterns surrounding the sufferer. The present study suggests a broadening in understanding the drama of suffering, and emphasizes how the cultural influence needs to be taken into account in the assumptions that underpin the theory of caritative caring.

*Suffering is enclosed in cultural patterns affecting how it is expressed, interpreted, understood and relieved, and the patterns form a drama with roles familiar to, but not always conscious to all counterparts.*

## 12. Critical review of the study and closing discussion

The present study is conducted in the caring science tradition. Caring science is seen as an autonomous science with an ontology and epistemology of its own. The ontology reflects reality and how it is viewed. Caring science ontology directs the research movement to further discover and develop topics of interest. It is visible in the language used and the outlook of research and methodology on research. The tradition of trans-inter-cross-cultural studies is new in Finland and few studies have been done within caring science of which none at Åbo Academy University.

The present study combines a theoretical perspective founded in caring science with an empirical study conducted in China and the specific aims for the study are firstly to depict the cultural patterns in how suffering is experienced and expressed among patients and relatives and how generic care practices are delivered, and the meanings values and beliefs that direct the practices. The second aim concerns the nurses and the cultural patterns are seen in the professional care, practices, meanings, values and beliefs when caring for the suffering patient. The influence of the social structure is discussed, aiming at getting a deeper understanding of cultural practices, meanings, values and beliefs and how they are seen in a cultural perspective.

The cultural perspective brings new concepts and a different way of viewing reality mirrored in caring science. The study attempts to broaden an understanding of suffering and caring through a cultural perspective in caring science as it has been developed at Åbo Academy University. This creates several difficulties which require humility in evaluating the relevance and importance of the study in order not to ascribe it too high importance. Firstly there is no ready made path to follow (methodology and method for transcultural intercultural and cross-cultural studies in caring science), which increases the risk of getting lost. To get lost can create new paths (consciously using a theoretical perspective developed in caring science and mirroring findings from an empirical study concerning suffering care and caring in another culture with different values and beliefs). This can create new substantial and methodological insights when finding the way back. It can also however create paths which are irrelevant to caring science. Concepts, which are not used in caring science are used in new constellations (such as “culture care descriptor”, “thick descriptions” “communication as caring act”) but no further analysis is carried out to discover whether or not they are congruent with the ontology and epistemology of caring science in this study. The study does not partake in the discussion of the accuracy of using the concept “transcultural nursing” or



“intercultural nursing”. This discussion is necessary for further development of caring science, and is an aim for further studies (cf. Jansen, 2006). All this could be seen as weaknesses in the study and possibly required further investigation (cf. Duffy 2001; Davidhizar et al., 1999; Gustafson, 2005; Jansen, 2006; Swendson, 1996). The motivation for doing it this way is to find new paths and new insights and then test them. Bravery and some foolhardiness are needed to create discussions that either coincide with or contradict existing theories and findings in the necessity of discovering new insights, paths and concepts.

Secondly a study like this can only be seen as a pilot study pointing in different directions, but several studies are needed to manifest a certain perspective, insight or recognition of a part of reality. The results of this study are congruent with previous research concerning the Chinese culture and the Chinese nurse’s view of their job (Chen, 2001; Kao & al., 2006; Mok, 2001; Mok & Tam 2001; Pang, 1998a, 1998b). The study is also partly congruent with previous research concerning suffering (among others Arman & Rehnsfeldt, 2007; Cassell, 1996; Charmaz, 1999; Cope, 2000; Eriksson, 1987, 1994, 2001, 2006; Fagerström, 1999; Fredriksson, 2003; Kleinman & al., 1997; Leininger, 1991, 2002b, 2005a; Morse, 2001; Morse & Carter, 1996; Morse & Doberneck, 1995; Rehnsfeldt, 1999; Sumner, 2001; Wiklund, 2000) although differences are found, which can open up for new questions.

The study is conducted using ethnography as method. The critical review of the study follows the qualitative criteria for evaluating ethnography studies created by Leininger (1991, 2002b, 2005a). The present study does not fall into the research method of ethnography, but the criteria are developed in a transcultural nursing research tradition and are therefore found to be usable for evaluating the relevance of an ethnographical study. The criteria are credibility, conformability, meaning-in-context, recurrent patterning, saturation and transferability. The criteria for evaluating the study will be presented one by one. The closing words include a discussion of the study’s relevance for the further development of caring science. This is the last subheading of the chapter.

## **Credibility**

Credibility refers to the “truth”; accuracy or believability of a study. Credibility implicates relevant interpretations and explanations of findings (Leininger, 2005b, 76). There are several sections in the study which influence the interpretation and explanation of findings. The research process is of vital interest when discussing credibility. The research process includes the development of pre-understanding, theoretical perspective of the study, methodology and

methods used for the data collection and analysis, and the final conclusions are made when the empirical findings are connected to the earlier research and theoretical perspective. The present study is a qualitative study, with interpretative ethnography as overall method. The qualitative approach is seen in the choice of data collection and analysis of data and in the attempt to achieve a deep understanding for the meaning behind actions.

Culture forms a frame for the study and the description of culture falls into a naturalistic, constructivist philosophy which is rooted in anthropology. The naturalistic approach is seen in the description of culture and the approach to the context being studied. Culture is seen as dynamic, constructed by people, and the interpretation aims at understanding the meaning of the actions of the human being in a given context. Interpretative ethnography leans on a hermeneutic foundation and the hermeneutic approach is often used in studies within caring science (Eriksson, et al., 2007). In the attitude to the pre-understanding, the description of the research process and the analysis of data the hermeneutic course of action is perceptible in this study. The hermeneutic approach allows creating a distance to the text (collected material transcribed to words). This is slightly different to Geertz's (2000a) description of handling collected material when he emphasizes staying grounded and that only short "flights" of ratification can be made when analysing cultural patterns. The present study could have benefited from a clarifying discussion of the hermeneutic approach in the chapter discussing methodological matters.

### ***Credibility in the theoretical part of the study***

The pre-understanding and theoretical perspective is the starting point for the interpretation of empirical findings in the present study. The presentation of the pre-understanding opens up for the reader to evaluate whether or not the interpretations are relevant and correct made. To make the pre-understanding explicit is not easy, especially since the study has been in process for a long time and the researcher's understandings of suffering, caring and cultural care have changed over time, and the resulting changes have influenced on the direction of the study. This creates both weaknesses and strengths in the study. One strength is that knowledge has developed over a long time and rests now on a solid foundation, however rudiments of previous (mis-) understandings may have influenced the study, although this is difficult to detect, since living with a study creates blindness to weak points. The study and the researcher are not the same today as they were six years ago. The perspective has changed due to development of the scientific area and personal insight, and a prolonged literature review may obscure and change the aim of the study due to new

results and different ways of viewing caring phenomena. The pre-understanding of the scientific area is developed in the earlier research findings regarding culture, communication, caring and suffering and in the theoretical perspective. These are described in chapters 2 and 3. The focus is on the suffering human being and caring practices. The emphasis is put on cultural influence on the practices which aim at alleviating suffering and achieving health. The theoretical perspective, founded in one culture can be strong and thus obscure the understanding of a phenomenon in another culture. A strategy to not let the theoretical perspective obscure the obvious truth is to be aware of the risks and try to prevent them by having a critical approach to what is detected. Although the theoretical perspective might obscure truths and create misunderstanding in a study like this, the choice has been to do it this way. When conducting a study in a foreign culture the “seeing” is built upon the understanding and the understanding has its foundation in a theoretical perspective and previous research findings. To let the reader follow every step in the research process and be aware of the researcher’s perspective and pre-understanding is a way of letting the study be evaluated.

Since the study is the first transcultural study at Åbo Academy University, chapter 4 concerning different directions in this kind of studies was presented. This chapter was not necessary to understand the result of this study, but was important for clarifying this specific area in caring science and was therefore included in the study. A brief presentation of Chinese culture was written in chapter 5. The pre-understanding concerning the Chinese culture was learnt by reading and spending time with people from China. The presentation of Chinese culture was narrow and directed. Many interesting aspects of the Chinese culture were excluded, but due to limited space in a dissertation, a deep description of the culture was impossible to conduct and also regarded as unnecessary. The empirical understanding of the culture as it is manifested was developed through visits to Fujian province and by learning from people who live there. The empirical pre-understanding in an ethnographic study is of an etic nature. The emic understanding is learnt through living with and learning from people and this is visible in the empirical part of the study.

The overall method used for the study was interpretative ethnography (as it is described by Geertz, 2000a) aiming at understanding the meaning of the caring practices. Interpretative ethnography was seen as a good method for learning about people, when the aim was to understand the meaning behind practices. Culture is within and among people. It was on the one hand constantly changing and on the other hand consistent. Actions have to be understood on a deep level to make sense and in order to be able to form “thick descriptions”. Geertz

(2000a) does not describe practical ways of doing ethnography, so several references were used when deciding the practical procedures of data collection, data analysis and presentation of results. The references were connected to ethnographical research and showed it from different angles.

The ethical principles were outlined in chapter 7 and special emphasis was put on international nursing research. It is always a risk to involve human beings in a study, and an even bigger risk to involve people from a different culture, where nursing research is uncommon. The different strategies for following ethical principles were outlined in chapter 8; the procedures for the empirical study. To what extent have the informants told me what they think I want to hear? To what extent have the “door-openers” influenced the informants’ decisions to participate? How can I avoid causing harm to the people I have met and to the society I have learnt to know? These questions were vital to the credibility. To not cause harm was a responsibility for the researcher. In order to assure that the society and the informants were not harmed and that there were no obvious misunderstandings or misinterpretations two independent Chinese persons have reviewed the manuscript before it was published.

### ***Credibility in the empirical part of the study***

The “truth” of the empirical part of the study lies in the methodology, the competence to conduct a study based on the described methodology and on the research methods used for collecting data and analysing data.

Methods for data collection are described in chapter 9. Traditional ethnographic data collection methods were used such as observation, participative observation, discussions and conversations following recommendations for conducting an ethnographic research (Hammarstam, 1990; Mulhall, 2002; Paterson & al., 2003; Pellatt, 2003; Rooper & Shapira, 2000 among others). The group discussions carried tenets from focus-group interview method as guidelines (McDaniel & Bach, 1994; Robinson, 1999; Tillgren & Wallin, 1997). The informants were patients, relatives, Hu Gongs, nurses, doctors and persons who were not active in a hospital milieu. The later group were informal informants, information was gained through conversations. The amount of informants was sufficient and the necessary information was gained, although saturation could not be achieved (altogether 56 persons’ voices were heard in the study). Only two Hu Gongs have participated in discussions, although several act in observations. The Hu Gongs were too few in this study to satisfy the need for information. This was due to late recognition of Hu Gongs as an important group of informants. Several nurses acted as informants both in formal and informal

discussions and also in observations. The patients vary in age and gender. The selection of informants was as broad as possible, and the nurses at the wards chose the participating patients as well as the wards where the observation and participative observation took place (based on criteria set by the author). The informants represented various groups and different kinds of information. The suffering, care, and caring was discussed from several angles. All of the informants were rooted in the Chinese culture and had an emic understanding of care, caring and suffering.

All discussions and conversations were held with the help of co-researchers. When collecting data through a co-researcher there is always risk for misunderstanding, misinterpretation and superficial data collection. To avoid this, the co-researchers filled criteria such as having knowledge of both Finnish and Chinese culture (this helps the co-researcher to understand the aim of the study and to correctly translate the discussions, but it might also direct the information), speaking both Mandarin and English and knowing the Chinese nursing culture well. The work with translators and co-researchers followed the suggestions made by Temple and Edwards (2002). The author had no possibility to choose the informants, which also might have influenced the outcome of the study. Most of the nurses acting as informants spoke both English and Mandarin. The informants might have shown a different view of caring and suffering from those who do not speak English, and therefore have no possibility to be influenced by English texts and materials. This does not represent the average nurse in Fujian province which also might influence the study, and give a coloured picture of the nurses' job. The informants who know English well have seen different models for caring and alleviating suffering since they have often been abroad. This kind of bias is difficult to avoid when the researcher learns from the informants and builds insights and "thick descriptions" based on gained information. The strategy to avoid the biases mentioned above in the study was to see phenomena from different angles and present a picture constructed by several groups of informants and not based only on a single informant's opinion or observation.

To conduct a study in a foreign culture and country demands bravery, from both the researcher and the people acting as informants. When the researcher is alone in a foreign milieu where the language and culture are not familiar, it creates dependency on other people. This creates openness and willingness to learn to know people and learn from people. The focus is then total on the commission, nothing in daily life disturbs. Being a foreigner creates the risk of misunderstandings and they are difficult to detect, since what the researcher does not know or understand is difficult to discuss. The informants did not in-

tentionally mislead the researcher, but some phenomena in daily life can be so obvious and unconscious for the informants that they forgot to inform about it and the nuances may be overlooked in observations.

It could have been difficult for the informants to meet a foreigner and talk about the most difficult parts of life, namely suffering and alleviation of suffering. This goes against the cultural norm of exposing oneself to foreigners. It creates a tension between the researchers "want" to learn from the informants and the informants' cultural values of not exposing themselves. This might create a superficial understanding of the phenomena. Not being familiar with the researcher and meeting a person who was totally focused on the individual could also create an open atmosphere and a willingness to share moments of life with the foreign researcher. To be a target was for many of the informants in this study the same as to be appreciated and valuable and the informants did openly share different and difficult situations that had happened in their lives, with the author.

## **Confirmability**

Confirmability means reaffirming what the researcher has heard, seen or experienced with respect to the phenomena under study (Leininger, 2005b, 77). In this study confirmability is discussed in relation to the analysis of the results found in the empirical part of the study. When analysing the data collected concerning the nurses daily life, it was important not to be ethnocentric. The risk was obvious, being a nurse myself. It was important not to place the own values on the Chinese nurses' work, in order to avoid cultural impositions and blindness and to avoid harm by misunderstanding cultural values, meanings and beliefs among nurses.

The first analysis of the collected data was done simultaneously as it was collected. This was in accordance with the ethnographic research method (cf. Roper & Shapira, 2000; Spradley, 1979). New questions arose and directed the data collection. The next step was to find a meaningful way of dealing with the huge and diverse material (discussions, observations, conversations), although all material was transformed to text before analysing it. This was done by borrowing an idea of presenting results from Leuning et al (2002). "Cultural care descriptors" was used as a concept describing the specific tenets showing cultural care practices.

The analysis of the material followed Geertz (2000a) approach for how to form "thick descriptions" of actions. The first phase in the analysis was to compile

the material based on what the informants were doing. The next phase was to learn to know the material enough to be able to formulate how informants were doing what they are doing. The third phase consisted of finding out underpinning values and this was done with help of literature. The last step was to find out the underpinning values of the beliefs and the beliefs hold the knowledge of “thick descriptions”. Following Geertz (2000a) and Spradley (1979) the natural way of presenting an ethnographical study is in the form of an essay. Writing a scientific essay aiming at showing the different steps in the research was not a practical option. The solution was to let the chapters where presenting the findings be a part of the study partly following an essay-writing style, which gave the presentation a personal touch.

“Thick descriptions” are a key to understanding phenomena under examination. All generic and professional care practices have a meaning (cf. Geertz, 2000a) and the “thick description” was formed by letting all counterparts be seen in the description of the practices and meanings related to suffering, the values that underpinned the alleviation of suffering and the beliefs that directed actions for the alleviation of suffering. This was done by analysing all the material together. Through this procedure the relatives, patients, Hu Gongs, nurses and field notes was clustered, and the different counterpart’s voices was heard and through this “thick descriptions” of practices were formed. The risk for misunderstanding was smaller when the same procedures were verified by several references, nurses, relatives, patients and by observations. However, this study was built on rather short stays in a culture, and conducted through a co-researcher, which both can be sources to superficial knowledge. This study can generate discussions about methodology in ethnographic studies, and the link between cultural competence, cultural values and caring science.

## **Meaning-in-context**

Meaning-in-context refers to the significance of interpretations and understanding of actions symbols, events, communication and other human activities within specific or total contexts in which something occurred or happened (Leininger 2005b, 77). In this study the meaning-in-context was discussed in relation to the interpretation of the empirical findings related to theoretical perspective and earlier research. The findings concerning suffering and practices which aim at alleviating suffering and reaching harmony or health were presented in chapter 10. Geertz (2000a) says that a theory developed in one culture cannot be transferred to another. It is therefore hazardous to try to understand the Chinese patient and his/her suffering based on a pre-understand-

ing rooted in the Western culture. Although the risk for misinterpretation was obvious some connections will be pointed out.

Firstly the patient's, relative's and Hu Gong's voices were heard. Cultural care descriptors describe what the patients, relatives and Hu Gongs were doing, patterns formed the statement "how they do what they do" and themes answer the questions of "why they act as they do". The themes formed values that underpinned the thick descriptions, in this study described as beliefs. The findings were connected to the earlier research and to the cultural structure dimensions which describe Chinese society. The earlier research was mainly done in a Western culture and the empirical findings originate from an Asian culture. The connections showed differences in values and beliefs underpinning the culture care practices, but the earlier research also created a new understanding for the patient's and relative's way of understanding and facing their own suffering. Morse (2001, 2002) and Morse and Carter (1996) who described the two behavioural stages of suffering opened up for understanding the Asian way of adapting oneself to suffering, and Eriksson (1992, 2006) in her description of the drama of suffering supplied an understanding for another drama with other phases which aims at reaching harmony. The fact that there are differences in understanding suffering and caring in different cultures, open up for understanding the need for a culturally congruent and competent care which is described by Campina-Bacote (1998, 2007) and Leininger (1991, 2002b, 2005a). This shows that research findings in one culture can enrich understanding of other empirical findings in another different culture.

Secondly, the nurses' voices are heard and their practices aiming at alleviating the patient's suffering are present. The material collected was presented in themes with patterns and cultural care descriptors illustrated by quotations from the original data. The beliefs formed thick descriptions that stated the understanding of why nurses acted as they did. They were striving for a professional approach in their work, and work through and with relatives and Hu Gongs. They aimed at delivering the best possible care to patients. This moved the focus for the nurse from being a support for the patient to being a support to the family. The nurse's professional skills are important while the nurse's ability to function as a compassionate carer slips into the background. The communication with relatives and patients becomes a caring act. The study shows that Chinese nurses' care practices differ from the Western ideal where caring is seen as an art (Nåden 1998) and where the caring discussion (Fredriksson, 2003) is directed to the patient in order to support the patient to go through the drama of suffering (Eriksson, 1992, 2006; Wiklund, 2000). This study can only be seen as a pilot study and further studies are needed to confirm these tenets.



## **Recurrent patterning and saturation**

Saturation means that the researcher has conducted an exhaustive exploration of whatever is being studied and recurrent patterning refers to repeated instances, sequences of events, experiences or lifeways that tend to re-occur over a period of time in designated ways and contexts (Leininger, 2005b, 77). Saturation in this study was not reached, when saturation is defined as an exhaustive exploration of what is being studied. Several informants participated in the study and each of them have a story of their own and several other stories with other patients, relatives, Hu Gongs and nurses were not told due to time limit. Recurrent patterns were seen, and the patterns form the values and beliefs (thick descriptions). Recurrent patterns were not formed by one informant they were formed by several informants and observations describing similar experiences but from different angles. The same patterns were found both times when the data was collected although 3 years passed between the data collection sessions. Recurrent patterns were important when forming thick descriptions. Without recurrent patterns it is difficult to understand the meaning behind the actions.

## **Transferability**

Transferability refers to whether particular findings from a qualitative study can be transferred to another similar context or situation while still preserving the particularized meanings, interpretations and inferences of the completed study (Leininger, 2005b, 77). This was penetrated in the analysis phase when findings from the present study done in an Asian culture, nourish the understanding of suffering care and caring in a Western culture and vice versa.

The study showed that it is not possible to transfer cultural interpretations as general truths; they are culture specific, which is also pointed out by Geertz (2000a). However gained knowledge in one cultural context can nourish theory development in another cultural context by using ideas sprung out of the interpretations, and by raising questions and viewing care, caring and the understanding of suffering from different angles. This was presented in chapter 11 when patterns of interpretations regarding human suffering care and caring arises and assumptions are formed. The patterns of interpretation are developed in both Westerns and Asian understanding of suffering and the care practices aiming at alleviating and relieving suffering. Assumptions concerning the nurse's professional practices were also formed and the assumptions motivated a care that was culturally competent in order to avoid cultural blindness and imposition. Cultural competence involves intercultural communication and the key was to understand the norms and rules of the culture. Anxiety, ethnocen-

trisms and assuming similarity instead of difference are barriers to intercultural communication and mutual understanding (Alexis & Chambers, 2003; Howard et al., 2001; Roux, 2002). Transcultural, intercultural and cross-cultural studies are needed in order to develop cultural competence and new insight to further develop caring science and theories.

## **Closing discussion**

The present study started with an emphasis on the importance of learning about diverse cultures to be able to care for the patient in a culturally competent way and to avoid ethnocentrism, cultural blindness and cultural imposition. This study has necessitated knowledge about different cultures in caring and nursing since there are patterns that cannot be understood and caring needs that cannot be met unless the caregiver is ready to learn from the people in a diverse cultural context. Is an etic understanding of culture enough to avoid cultural blindness and imposition in care for the suffering human being, or is understanding built on emic information always necessary? Is it possible to avoid ethnocentrism by being aware of one's own culture and open for learning about others? These questions arise at the close of the present study and there is a need for further study to find ways to avoid cultural blindness, imposition and ethnocentrism in care.

The present study aims at describing cultural care practices and values and beliefs underpinning the care practices in a Chinese context. The study focuses on both generic and professional care practices. The results from this study are presented in chapter 10 and can nourish the progression of caring science (as it progresses at Åbo Academy University) and modulate the assumptions underpinning the theoretical perspective for this study with a cultural perspective.

The experience of suffering might differ depending on cultural belonging. Culture can be seen as a filter through which suffering has to be interpreted and understood and through which the alleviation of suffering has to be delivered. The discussion in the present study is a beginning and a basis for further development of knowledge of the influence of culture in the understanding of the suffering human being, which is one of the corner stones in this research. Assumptions regarding suffering and descriptions of the drama of suffering can be broadened in order to carry the diverse understanding of going through the different phases in the drama of suffering described in the present study. The caring relationship can also be extended to involve not only the patient and the nurse but also the family, since not all cultures are focused on the individual, cultures can be focused on the benefit of the group ahead of the benefit

of the individual. This is an important part to discuss in nursing education, since the nurses have to be open for different constellations in the concept of patient.

The present study necessitates the importance of including the family as caregiver and care recipient and the necessity of culturally competent care to the theory of caritative caring. The cultural perspective is neither much discussed, nor is any studies published concerning the development of concepts linked to cultural care in caring science at Åbo Academy University.

Methodological matters benefiting transcultural, intercultural, or cross-cultural study have to be borrowed from other sciences. Interpretative ethnography has its roots in hermeneutics, a methodology commonly used in caring science (Eriksson & al., 2007) and interpretative ethnography helps the researcher to penetrate the meaning of actions and detect patterns not even conscious to the actors (cf. Geertz, 2000a). When interpretative ethnography is used, knowledge gained is of most interest in the cultural context in which everything happens. Generalizations are not suggested by Geertz (2000a) and are not seen as realisable in this study except for generalising ideas that can be transferred through cultural borders.

The findings from this study can hopefully inspire the nursing leaders and researchers in China to develop models and methods that can be used in a Chinese context aiming at alleviating or relieving suffering. The Western models and methods can only be a superficial tool for care in a Chinese context since the values underpinning Western models differ from the values of the context in which the models are to be applied. The practices seen with a foreigner's eyes can open up for a deeper understanding of the suffering human being. Knowledge gained in an interpretative ethnography conducted in China can also inspire the development of a caring theory in a Western culture.

In China today it is interesting to see the development of caring in nursing since the traditions direct the family to care for the sick person and the modern nursing profession includes caring elements. The challenge in China, as well as in all other parts of the world, is to develop nursing in such a direction that the patient experiences the care as if it were administered by his/her own family (cf. Wong & Pang 2000).

Interpretative ethnography is borrowed from anthropological philosophy and carries elements from another science than caring science. It is of interest to continue the discussion, opened by Jansen (2006) about the roots of the meth-

odologies and methods used in caring science. Borrowed methodology and methods carry concepts and solutions that can be anomalies in caring science which need to be further investigated but there is also a need to test and create new concepts describing a diverse reality also in caring science

# SAMMANFATTNING

## **Traditionellt och professionellt vårdande i en kinesisk kontext.**

En etnografisk studie

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## **Introduktion**

Studien syftar till att upptäcka kulturella mönster i hur lidandet upplevs och beskrivs bland patienter och anhöriga i en kinesisk kontext, samt hur den lidande människan vårdas av både familj, anhöriga och professionella vårdare. Studien fokuserar på de motiv och värderingar som avspeglas i tolkningen och förståelsen av lidande och den vård som syftar till att lindra lidandet. Den traditionella vården representerar den vård som utförs av familj och anhöriga och som bygger på en kunskap som förs över från en generation till en annan ("generic care" beskriven av Leininger 2005a, 14). Den professionella vården representeras av vård given av för ändamålet utbildad personal som utövar sitt yrke ("professional care", beskriven av Haigler, Baure & Travis 2004). Studien relateras till den sociala struktur som finns i den kontext där den empiriska studien genomförts och ger därigenom en djupare förståelse för den vård som förmedlas av vårdare och anhöriga som utgör patientens familj.

Studiens frågeställningar är följande:

1. Hurdan är den kulturellt betingade traditionella vården bland patienter och deras anhöriga i en kinesisk kontext och vilka motiv och värderingar påverkar vården?
2. Hurdan är den kulturellt betingade professionella vården i en kinesisk kontext och vilka motiv och värderingar ligger som grund för lindrande av lidande i professionella vården?
3. Hur påverkar den sociala strukturen i en kinesisk kontext upplevelsen av och uttrycksformerna för lidande och vårdande?

## **Teoretiskt perspektiv**

Den föreliggande studien har sin utgångspunkt i en autonom vårdvetenskap, utvecklad inom den humanvetenskapliga traditionen (jfr Lindström, Lindholm, & Zetterlund, 2006) där den caritativa vårdteorin (jfr Eriksson 1987, 1992, 2001, 2002, 2007) utgör en naturlig utgångspunkt för studien. En annan

utgångspunkt utgörs av Leiningers teori benämnd ”Culture Care Universality and Diversity” (1991, 2002b, 2005a, 2005b).

Lidandet ses som vårdens grundmotiv (Eriksson 1994, 2006) och kan beskrivas utgående från tre förståelsemodeller: det existentiella lidandet, lidande som består i avsaknad av vårdande och lidande som har sin grund i sjukdom eller behandling. Lidandet kan symboliskt beskrivas som ett döende. Den lidande människan kämpar för sitt liv och kan ensam eller med hjälp av andra förbli i sitt lidande eller finna en väg ut ur lidandet. Lidandet kan gestaltas i form av ett drama bestående av tre akter: bekräftelsen av lidandet, lidandet och försoningen. Varje människa är unik, och följaktligen är också människans upplevelse och förståelse av sitt lidande unikt, men uttrycksformerna för lidandet följer kulturella mönster. Den professionella vårdaren bär element av den traditionella vården (jfr Leininger 1991; Eriksson 1987). Enligt Leininger (1991, 2002b, 2005a) påverkar kulturen människors syn på hälsa, vård och välbefinnande samt hur vården organiseras och administreras i ett samhälle. För att förstå den enskilda människans uttryck för och förståelse av sitt lidande bör vårdaren känna till de generella mönstren i patientens kultur. Vårdandet har både en pragmatisk uppgift, att lindra lidande, och en symbolisk mening i en kultur.

## Metod

Det övergripande metodologiska närmelesättet i studien utgörs av tolkande etnografi inspirerad av Geertz (2000a, 2000b, 2000c). Tolkande etnografi har sin utgångspunkt i hermeneutiken. Studien utgår från ett insiderperspektiv. Att enbart beskriva de observerade fenomenen ger enligt Geertz (2002a) en ytlig eller tunn förståelse. För att nå en djupare förståelse av en handling bör också frågan om ”varför” handlingen utförs tolkas och förstås. Frågor som ”vad”, ”hur” och ”varför” kan användas för att skapa en djupare förståelse eller med Geertz ord en tät beskrivning av en händelse. Då skapas en beskrivning och en tolkning av händelsen som säger varför handlingen utförs, vilken mening den bär samt vilka värderingar och trosföreställningar som styr handlingen.

Studien har en kvalitativ forskningsdesign. Det teoretiska perspektivet har utvecklats i en västerländsk tradition med litteratur i första hand producerad i Norden och Nordamerika. Den empiriska studien har utförts i en asiatisk kultur och avspeglar en kontext i sydöstra delen av Kina. Mötet mellan två kulturer skapar ett spänningsfält där tolkningen av upplevelser och förståelsen av lidande och vård möts. Tolkningen av det erhållna empiriska datamaterialet bär element av både den västerländska och österländska kulturen och traditionen.

## Etiska överväganden

En etnografisk studie kräver speciella etiska överväganden under forskningsprocessen. Etnocentrism hos forskaren kan leda till felaktigt tolkade och rapporterade resultat och kan därigenom skada informanterna och samhället. Enligt ICNE (International Centre for Nursing Ethics) bör det lokala samhället, där forskningen bedrivs, ges möjlighet att påverka hur forskningen genomförs. Forskningen bör också kunna påvisa en nyttoaspekt för det samhälle där den utförs, och det bör kunna motiveras varför den grupp informanter som medverkar i forskningen har valts ut (Olsen, 2003). I den föreliggande studien hade de sjukhus där studien genomfördes en aktiv roll i att välja ut de informanter som deltog och de sammanhang där datainsamlingen kunde utföras. Datainsamlingen gjordes tillsammans med personer som var väl förtrogna både med forskningens syfte och den kontext där den utfördes (medforskare). Manuskriptet har därtill lästs av två personer som känner den kontext där studien har utförts innan publicering för att undvika att missförstånd och felaktiga tolkningar sprids. Studien är skriven på engelska för att den skall kunna komma till användning även i en kinesisk kontext.

## Genomförande

En etnografisk studie är tidskrävande, och föreliggande studie har genomförts under en period av tio år. År 1997 besökte jag provinsen Fujian första gången och forskningsintresset väcktes. Under 1998 besökte jag provinsen två gånger, bägge gångerna som gästföreläsare. År 1999 gjordes en forskningsplan och under ett besök i provinsen genomfördes två pilotstudier för att klargöra förutsättningarna för att genomföra den planerade studien. Pilotstudierna visade att studien var möjlig att genomföra. Samma år presenterades forskningsplanen på en internationell vårdkonferens i Beijing. År 2000 gjorde två studerande från Svenska yrkeshögskolan sitt lärdomsprov i Kina. Lärdomsprovet finns som en del av förförståelsen för studien. År 2002 gjordes de första tematiska diskussionerna på tre sjukhus. I diskussionerna deltog patienter, anhöriga och ”Hu Gongs”. ”Hu Gong” betyder ”vårdande arbetare”, och patienten eller de anhöriga hyr en ”Hu Gongs” tjänster för längre eller kortare tid. En ”Hu Gong” har ingen formell sjukvårdsutbildning och är inte anknuten till sjukhuset men lever med patienten på sjukhuset under patientens vistelse där och kan ses som ställföreträdande anhörig.

Som datainsamlingsmetoder har observation, deltagande observation, tematiska diskussioner och fältanteckningar använts. Under 2003–2004 gjordes fortsatta datainsamlingar, främst i form av tematiska diskussioner med enskilda personer, främst vårdare på de sjukhus där datainsamlingen utfördes. Besöken

på sjukhusen gjordes i samband med gästföreläsningar. År 2005 gjordes en första grov analys av de erhållna data och därefter samma år en klagörande diskussion med patienter, vårdare och anhöriga två av de sjukhus där den tidigare datainsamlingen med patienter gjorts. Under 2006 och 2007 har resultaten bearbetats och studien färdigstälts.

Analysen av datamaterialet började med genomläsning av det transkriberade materialet. Därefter sammanställdes kluster som beskrev händelser (svarar på frågan ”vad händer”) och de benämndes kulturella beskrivningar (”cultural descriptors”). Det följande steget i analysen var att beskriva mönster (”patterns”) som kunde skönjas i händelserna (svarar på frågan ”hur”), och slutligen formades tema (”themes”) kring de mönster som händelserna bildade (svarar på frågan ”varför”). De teman som formades är samtidigt det som Geertz (2002a) beskriver som ”thick descriptions”.

## Resultat

I den empiriska studien deltog sjukskötare, ”Hu Gongs”, patienter och anhöriga. I den ursprungliga planen fanns inte ”Hu Gongs” med som informanter, men under forskningsprocessen framsteg de som en väsentlig del av den kinesiska sjukvården och införlivades därmed i studien.

Resultatredovisningen presenteras i tre kapitel där det första underkapitlet beskriver patienternas, anhörigas och ”Hu Gongs” upplevelser av lidande och vård. Det andra underkapitlet fokuserar på vårdarna samt deras upplevelser av lidande och vård, medan det tredje underkapitlet sammanfattar den sociala strukturens påverkan på upplevelsen samt förståelsen av lidande och vård.

Studiens första frågeställning berör den kulturellt betingade traditionella vården bland patienter, anhöriga och ”Hu Gongs” i en kinesisk kontext. Frågan söker svar på hurdan den kulturellt betingade traditionella vården bland patienter och deras anhöriga är samt de motiv och värderingar påverkar vården. Nedan används begreppet ”anhörig” som beskrivning på en medlem av den familj till vilken patienten hör.

Sex olika teman framträder. Det första temat är samhörighet – att inte bli övergiven. För den kinesiska familjen, som framträder i data materialet, är det viktigt att hålla samman. Den insjuknade familjemedlemmen skall inte känna sig övergiven utan känna samhörighet med familjen och livet utanför sjukhuset. Att ha en anhörig med på sjukhuset är viktigt och det kan ses som att hemmet flyttar till sjukhuset och de anhöriga turar om att vara med patienten, vid



behov dygnet runt. De anhöriga kommer med mat till patienten, övervakar medicinering och intravenösa infusioner, ser till att patienten kommer till konsultationer och behandlingar och hjälper patienten med den dagliga hygien om det behövs. Allt detta kan överföras på en ställföreträdande anhörig, en ”Hu Gong”, som utför anhörigas uppgifter om inte de anhöriga har möjlighet att vara tillsammans med patienten. En ”Hu Gong” kan vara anställd för tjänst hela dygnet eller för vissa delar av dygnet och skall vara som en son eller dotter för patienten.

Det andra temat berör integritet och privatliv då rummet är fyllt med människor. En sårbar och sjuk människa skall inte behöva exponeras fysiskt eller emotionellt. De anhöriga skyddar patienten på olika sätt, t.ex. i grundvården genom att skydda patienten från exponering då olika vårdprocedurer genomförs. Det kan te sig svårt då patientrummet ständigt är fyllt med andra patienter och deras anhöriga och nyfikenheten är stor. Integriteten och privatlivet blir symboliskt, och att skydda patienten från att bli emotionellt blottad blir lika viktigt som att skydda patienten från att blottas fysiskt.

Att inte åstadkomma skada är det tredje temat. Patienten skall skyddas från att visa ett emotionellt lidande och det kan ske om en patient får besked om sin sjukdom innan patienten är beredd på det. Att öppet visa rädsla eller sorg kan innebära att patienten ”förlorar ansiktet”. De anhöriga tar över och bär patientens lidande tills patienten är redo att själv möta det. De anhöriga avgör när patienten är mogen att få vetskap om sin sjukdom. Läkare och vårdare diskuterar inte patientens sjukdom direkt med patienten, utan diskussionspartnern är de anhöriga, eftersom man vill undvika det emotionella lidandet innan patienten är beredd på den situationen. Att patienten får reda på sin diagnos kan förorsaka skada, eftersom patienten kan förlora sitt hopp om sjukdomen är allvarlig och livshotande till sin karaktär.

Trygghet och tillit är de två följande temana. Det upplevs som ett värde i sig att dela med sig av sin tid och att upprätthålla traditioner. De anhöriga är patientens röst och garanterar att patienten får en god vård. För att patienten skall tillfriskna är tilliten till vården viktig. Patienterna litar på vården trots att de är medvetna om att de inte har full insikt i alla beslut. Tilliten bygger på tilltron till att de anhöriga kan garantera att patienten får så god vård som möjligt.

Det sista temat är harmoni. I den kinesiska kontexten strävar man efter att uppnå harmoni. Harmoni är viktigt för att uppnå hälsa och välbefinnande. Hopp och harmoni hör samman och är beroende av varandra. Inom vården skall

patienterna uppmuntras till att ha en hoppfull attityd till sin situation för att därigenom kunna uppnå harmoni. I den kinesiska kulturen finns en tilltro till att patienterna medvetet kan påverka sitt liv och sin situation. Man kan välja att förhålla sig positiv till livet och därigenom uppnå harmoni och balans.

Den kinesiska patienten framstår vid analys av datamaterialet som tillbakadragen. Patienten tar inte aktivt del i beslut som fattas inom vården, lämnas inte ensam och har ständigt en anhörig vid sin sida som är redo att försvara patienten. Den traditionella vården är viktig i en kinesisk kontext, och familjen kan ses som den primära vårdgivaren (jfr Haigler et al. 2004; Wang & Pang 2000). Alla familjemedlemmar är viktiga för varandra och familjemedlemmarna har olika roller då en familjemedlem insjuknar. Denna tolkning stöds av Wong och Pang (2000) och kan hänföras till att i Kina får en person sitt värde i relation till sin roll i en grupp, familj, i att vara en del av en helhet (jfr Kao et al. 2006; Jakobsson 2001). Familjen lider med patienten, och i en kinesisk kontext lider familjen också för patienten (jfr Tapp, 2001; Smith, 1998; Mok, 2001). Familjen är en garant för god vård, vilket också poängteras av Bondas (2000) och Haigler et al. (2004), som beskriver familjen som en viktig part i vårdprocessen. Familjen behöver stöd för att klara av vården (jfr Winslow, 2003), och stödet är naturligt förekommande i den kinesiska kontexten. Viktiga ärenden diskuteras inom familjen, och respekten för de äldre i samhället är tydlig (jfr Finn & Lee, 1995). Den primära vården är familjens interna angelägenhet och avspeglar den sociala normen att inte exponera patienten för främlingar. Familjen stöder den sjuka att tänka positivt och undviker att utsätta den sjuka för dåliga nyheter, eftersom det negativt kan påverka sjukdomsförloppet. Att vara glad och att göra gott för den andra är ett viktigt värde i den kinesiska kontexten (jfr Chen, 1996, 2001).

Lidandet ses som en naturlig del i livet (jfr Eriksson 1994, 2006). När man talar om lidande finns också hälsan närvarande (jfr Chen 2001). Lidandet ses som disharmoni (jfr Chen, 1996, 2001; Kao et al., 2006; Mok, 2000) och genom att öppet visa lidande sprids också disharmonin, och därför lider de flesta i det tysta. Då kan en skenbar harmoni uppnås. Patienter undviker att ifrågasätta en behandling eftersom man vill undvika konflikter (jfr Chen, 2001), medan familjen kan agera som patientens ombud och framföra klagomål över t.ex. uteblivet vårdresultat till ledare för sjukhuset. Samarbete är en viktig del i behandling och vård, och patienten är inte en oberoende part i samarbetet med läkare och vårdare, eftersom information om sjukdom och behandling undanhålls patienten. Patienten måste därför lita på de anhörigas förmåga att fatta rätt beslut i situationen och läkarens kunskaper att ge den rätta behandlingen utan att själv aktivt kunna påverka situationen.

Morse (2001) beskriver lidandet som bestående av två faser benämnda ”uthärdande” och ”emotionellt lidande”. Den kinesiska patienten i den föreliggande studien visar många likheter med det som Morse benämner ”att uthärda” i offentliga sammanhang, medan det emotionella lidandet endast visas för den närmaste familjen, om det överhuvudtaget visas. Vetskapen om att en sjukdom är livshotande gör att hoppet dör, och därför undanhålls sanningen om patientens tillstånd för patienten. Hoppet kan inte existera samtidigt som rädslan, och därför beskyddas patienten från att förlora sitt hopp. Den kinesiska patienten lever inte genom sitt eget lidandes drama utan beskyddas från detsamma (jfr Berry, 1999; Bondura et al., 2001; Eriksson, 2006; Wiklund, 2000).

Ur materialet stiger sex trosföreställningar, som har avgörande inverkan på den traditionella kulturellt betingade vården. Den första trosföreställningen är en sjuk människa behöver beskydd och den andra familjen garanterar en god vård. Vårdare och läkare ansvarar för den professionella vården, som är inriktad på fysiska och tekniska vård åtgärder. Den tredje trosföreställningen berör familjen och innebär att familjen måste ta ansvar för sjuka medlemmar. Familjen är en viktig institution i det kinesiska samhället, och det är familjen som bär det primära ansvaret för vården av en anhörig. Lidandet är uthärdligt om det finns harmoni är den fjärde trosföreställningen. Patienten påverkar själv medvetet sin upplevelse av harmoni genom att tänka positivt och skjuta undan rädsla. Den femte trosföreställningen är att patienten skall ständigt sträva efter att uppnå harmoni. Samhällets eller gruppens behov ställs framom de individuella behoven är den sjätte trosföreställningen och den kan åskådliggöras med tanken om att gruppens harmoni är viktigare än den enskilda individens disharmoni, vilket gör att den som lider inte offentligt sprider sitt lidande eftersom det förorsakar disharmoni i gruppen.

Den andra frågeställningen för studien berör den professionella vården i provinsen Fujian i Kina. Syftet är att beskriva hurdan den kulturellt betingade professionella vården är och vilka motiv och värderingar som ligger till grund för lindrande av lidande i den professionella vården. Nedan beskrivs de olika teman som stiger fram ur datamaterialet som berör relationen mellan vårdare och patient.

Det första temat är förpliktelse att utöva professionell vård som står i samklang med de värderingar som är förhärskande i samhället. Vårdaren har ett paradigm där tillfrisknande, botande och helande är förhärskande, vilket innebär att vården fokuserar på teknisk skicklighet och en stor tilltro till teknik och medicin. Vårdaren skall vara positiv och överföra sin harmoni på patienter som lider

brist på harmoni. Vårdaren skall stöda patienten att uthärda sitt lidande och undvika att frammana uttryck för emotionellt lidande, vilket inte är önskvärt i den kinesiska kontexten.Handledning av unga och nya vårdare anses vara viktig för att de skall tillägna sig ett professionellt förhållningssätt.

Det andra temat berör kommunikation som ses som en viktig del av vårdandet. Patienten och de anhöriga är i fokus, men också kommunikationen mellan olika personalgrupper är viktiga i vården. Kommunikationen med patienter och anhöriga reflekterar vårdarens yrkeskunskap, och kommunikationen sker ofta i form av undervisning, handledning och stöd för anhöriga i hur de skall vårda patienten.

Det tredje temat berör hjälplöshet och hopp. Lidandet involverar hela människan och gör henne hjälplös. Hopp förutsätter harmoni vilket behövs då människan skall möta motgångar i form av sjukdom. En patients lidande berör förutom patienten och familjen också vårdaren. Patientens lidande är i första hand en familjeangelägenhet, och en professionell hållning hos vårdaren innebär att låta patienten uthärda sitt lidande tillsammans med familjen och inte påverka situationen, förutsatt att vårdaren inte blir tillfrågad om hjälp. Att inte berätta hela sanningen för patienten kan sägas vara en vit lögn, som är accepterade i Kina. Det är svårt för vårdarna att undanhålla sanningen om patientens tillstånd för patienten själv och samtidigt stöda patienten och familjen.

Det kinesiska ordet för sjukskötare betyder "beskydda och leda" (jfr Kao et al., 2006), och mycket av datamaterialet visar att vårdaren beskyddar sin patient från lidande och också leder vården. Det är viktigt att göra det goda för patienten samt att lindra lidande och smärta (jfr Chen 2001). Patienten ses som sårbar och vården skall stöda patienten genom att vara positiv. Det kan ta sig uttryck i att vårdaren inte visar sitt medlidande med en patient eftersom det kan göra att patienten förstår sin svåra situation och därigenom också lider emotionellt (jfr Morse & Carter, 1996). Patienters och anhörigas lidande påverkar vårdarna (jfr Barbato 2004, Rowe 2003), och vårdarna upplever själva lidande som är relaterat till patienter och till den sociala struktur som finns i den kontext där lidandet uppstår (jfr Eifried, 1998; Jezuit, 2000, 2001; Maeve, 1998; Morse, 1996b; Smith, 1998; Tapp, 2001; Rowe, 2003; White et al., 2004). Vårdaren upplever sig hjälplös då hon inte kan lindra lidande.

Vårdarens roll, såsom den stiger fram ur data materialet, är uppgiftscentrerad, hon har ett kurativt paradigm och uppskattar medicinsk och teknisk kunskap (jfr Kruijver et al., 2001). Vårdaren lider med patienten, och i medlidandet finns utrymme för vårdande. Vårdaren lider med och för patienten (jfr Morse

& Carter 1996), men vårdarens medlidande är dolt för patienten. Den vårdande handlingen kan ske genom det stöd de anhöriga får i form av undervisning, vilket i förlängningen också kommer patienten till del i form av god vård och anhörigas goda kontakt med vårdare. Vården i en kinesisk kontext är familjecentrerad samt familje- och patientledd. Leininger (1991, 1997a, 2002b, 2005a) diskuterar också det familjecentrerade närmelsesättet i vården och framhåller att man inte kan se patienten isolerad utan alltid bör ta familjen i beaktande vid vården av en patient. Vårdarna i studien upplever att patientens familj ibland kan ställa orimliga krav på vården och vårdarna (jfr Pang, 1998b), och de är medvetna om att de anhöriga kan rikta klagomål mot deras arbete till ledare på sjukhuset, en situation som vårdarna inte önskar skall uppstå.

Kommunikationen är viktig i vårdandet, och informanterna i föreliggande studie uppfattar kommunikation som vårdande (jfr Davis, 2001; Fredriksson, 2003; Graber & Mitcham, 2004; Kruijver et al., 2001; Manderson & Allotey, 2003). Vårdarna undervisar både patienter och anhöriga (vårdarna nämner inte "Hu Gongs" i detta sammanhang), och undervisningen hänförs då till kommunikation och vård. Att undervisa anhöriga underlättar för patienten och ger lindring i lidandet samt ger också de anhöriga en naturlig del i vården (jfr Johansson et al., 2002; Hemsley et al., 2001; Stensland & Malterud, 1998). Undervisningen berör konkreta praktiska procedurer inom vården (jfr Kruijver et al., 2001), och undervisningen är nödvändig då anhöriga utför vård som kräver professionellt kunnande (jfr Haigler et al., 2004).

Vårdarna ger uttryck för etiska värderingar som att inte skada patienten, att respektera både familjen och patienten i vårdsituationen och att sträva efter harmoni. Dessa tre värderingar är genomgående synliga i datamaterialet. Att följa traditionen och att vara professionell i yrkesutövandet ses som instrumentella värden.

Fyra trosföreställningar stiger fram ur materialet. Trosföreställningarna kan sägas utgöra den djupa förståelsen för varför handlingar äger rum. Den första trosföreställningen är att lidandet är ett tecken på disharmoni, och vården syftar till att återupprätta eller överföra harmoni och hopp till patienten. Enligt kinesisk filosofi är harmoni viktigt och en individs harmoni eller disharmoni påverkar hela gruppen. Gruppens behov ställs framför individens, vilket medför att allas harmoni är viktig för att gruppen skall uppleva harmoni. Den andra trosföreställningen är att genom att upprätthålla traditionen och de sociala normerna uppnås harmoni. Den tredje trosföreställningen berör att göra det goda för patienten, och det är en moralisk förpliktelse att arbeta för patientens bästa. Vårdarna lägger stor vikt vid yrkesskicklighet samt att hela och bota pa-

tienten. Medlidande för patienten visas i symboliska handlingar och genom att vårda patienten genom anhöriga. Den sista trosföreställningen är att sjukdom och lidande är en familjeangelägenhet och skall inte exponeras för främlingar. Trosföreställningen har sitt ursprung i kinesisk tradition och filosofi som berör harmoni, familj och att kontrollera känslor. Den ekonomiska situationen i Kina påverkar trosföreställningen, eftersom det är familjen som avgör vilken vård de har råd med.

Vård och vårdande är en naturlig del av kulturen och ingår i den sociala struktur som formar samhället. Den sociala strukturen påverkar vårdens innehåll och utformning, och vården påverkar och utvecklar kulturen (jfr Leininger, 1991, 2002b, 2005a). Informanterna i studien beskriver olika former av lidande varav ett benämns socialt lidande, vilket också beskrivs av Kleinman, Das och Lock (1997). Det är orsakat av politisk, ekonomisk och institutionell makt. I Kina är sjukförsäkringssystemet inte ännu utbyggt, och de flesta är tvungna att betala sin sjukhusräkning själv. Familjen står för alla kostnader som förorsakas av sjukvården, och om familjen inte har pengar lånar man, och det här leder till ohållbara situationer. De som inte har råd med sjukvård står utanför vårdssystemet, och vårdaren kan vara den person som är tvungen att meddela patienten att vården avbryts eller inte påbörjas på grund av patientens ekonomiska situation. Det här kan jämföras med det som Leininger (2002a, 1997b) benämner kulturell smärta. Den kulturella smärtan har sin grund i den kontext där den lidande människan befinner sig. Kön, klass och etnisk tillhörighet kan spela en roll i upplevelsen av lidande, och för de som har en ekonomiskt ohållbar situation ökar samhällets och kulturens sociala struktur det individuella lidandet.

Ännu är det en tradition i en kinesisk kontext att en nära anhörig vårdar patienten på sjukhuset och att vårdarna inte utför grundvård. I framtiden kommer inte de nära anhöriga att räcka till för att upprätthålla den traditionen (jfr Zhan, 2005; Wong & Pang, 2000) och det kommer att avspeglade sig på utbildning, rekrytering av vårdare och utbyggnad av hälsovårdssystemet. Det är möjligt att hyra en "Hu Gong" för grundvård och på så sätt upprätthålla en skenbar tradition av att inte behöva vårdas av en främling. "Hu Gongs" är lågavlönade, har låg status och saknar vårdutbildning; de är ställföreträdande anhöriga men har ingen möjlighet att påverka vården i någon riktning utan kan endast göra det som patienten eller de anhöriga ber dem att göra.

## **Slutledningar**

I diskussionen speglas den empiriska studiens resultat mot det teoretiska perspektivet. Den första slutsatsen är att familjen (de anhöriga) är naturliga vårdgi-

vare och vårdtagare som behöver uppmärksammas och få stöd och handledning av den professionella vårdaren för att kunna ta en naturlig del i vården av en sjuk familjemedlem och bli en del av vårdgemenskapen. En barmhärtig vård förutsätter kärlek till människan. I en kinesisk kontext är det familjen som står för den patientnära vården, där kärleken till människan är synlig och påtaglig (jfr Hsiao et al., 2005; Jakobsson, 2001; Kao et al., 2006), medan den professionella vårdaren är mer fokuserad på den rent yrkesmässiga skickligheten i sitt arbete. Människan ses alltid i relation till den grupp hon tillhör, vilket gör familjen mycket viktig för den som är sjuk (jfr Jakobsson, 2001). I Kina kan sjukhuset ses som den plats där anhöriga vårdar sjuka familjemedlemmar under vägledning och handledning av en professionell vårdare, samtidigt som den professionella vårdaren gör sitt yttersta för att med hjälp av teknik och skicklighet också bota och hela patienten. I den västerländska vårdtraditionen poängteras den vårdande relationen och beskrivs som ett samspel mellan patient och vårdare (jfr Eriksson, 1987, 1997, 2001; Fredriksson, 2003). Baserat på de resultat som den föreliggande studien presenterar är det nödvändigt att inom vårdvetenskapen närmare utforska familjens ställning i vården samt vårdarens möjligheter att stöda och vägleda familjen och därigenom ge familjen en synlig och erkänd roll i vårdandet av den lidande människan.

Den andra slutsatsen som lyfts fram är att kulturen är skapad av och påverkar människorna och den är i ständig förändring. Vården är en naturlig del av kulturen. Människors uppfattning om lidande är påverkad av den kultur de har vuxit upp i. I den kinesiska kontexten beskrivs lidande som fysiskt (försakat av sjukdom, olycka eller handikapp), psykiskt (försakat av att människan inte kan bemästra sin situation), existentiellt (förenat med tankar om död och religiösa grubblerier) och socialt (förenat med ensamhet, ekonomi och arbetslöshet). Enligt de kinesiska vårdarna är det lidande som förorsakas av sociala omständigheter det svåraste, eftersom ingen kan lindra det. Den föreliggande studien visar vikten av att ta den kulturella tillhörigheten i beaktande vid vården av patienter. Kulturen formar en ram inom vilken vården av den lidande människan sker, och kulturen ger också en ram inom vilken patient och vårdare möts. Vårdaren och patienten (de anhöriga, familjen) möts i en kulturell kontext där de motiv, värden och trosföreställningar om vård och vårdande alla parter bär med sig, påverkar skeenden i vården.

Den tredje slutledningen berör lidandets drama och stipulerar att lidandet är införlivat med kulturella mönster som styr hur lidandet uttrycks, hur det tolkas och förstås. Idén att förlikna lidandet med ett livets drama hämtas från Eriksson (1994, 2006), och i den kinesiska kontexten är rollerna klara och synliga. Rollerna är den medvetet omedvetna patienten som förlitar sig på anhörigas

förmåga att fatta rätt beslut, de optimistiska och glada vårdarna som stöder utvecklingen av harmoni och hopp utan att avslöja sanningen och som vårdar genom anhöriga för att patienten skall få en så adekvat vård som möjligt. Familjen (de anhöriga) har också sin roll i dramat och det är de som fattar alla beslut, bär patientens lidande tills patienten själv orkar och förmår bära det utan att bryta samman och lida så att hoppet försvinner. Den föreliggande studien påvisar ett behov av att närmare utreda lidandets drama (jfr Eriksson, 1987, 1994, 2001, 2006) och pröva dess innebörd också i andra kulturer än den nordiska.



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Otto Andersson (1879-1969) har en oomstridd position som auktoritet inom den finlandssvenska folkmusiken. Hans namn figurerar i så gott som all referenslitteratur som vetenskapligt eller populärvetenskapligt beskriver den finlandssvenska folkmusiken. Hans körarrangemang av folkvisor är ständigt återkommande, närapå obligatoriska inslag i finlandssvenska sång-och musikfestsammanhang. Avhandlingen analyserar och belyser Anderssons väg till denna viktiga ställning inom den finlandssvenska kultursfären. Samtidigt utreds också hans betydelse vid formandet av den normerade bild vi idag har av finlandssvensk folkmusik.

Detta görs med utgångspunkt i hans folkmusikaliska verksamhet i form av insamling, revitalisering och forskning, såsom den beskrivs i hans egna skrifter. Dessa texter, såväl opublicerat som publicerat material, analyseras i förhållande till den kulturhistoriska utvecklingen och samtidigt är också en biografisk dimension närvarande. Avhandlingen utreder alltså på vilket sätt en individ genom sin verksamhet och sina publikationer bidrar till formandet av det som i avhandlingen betraktas som en finlandssvensk folkmusikkanon.

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